Perceptions of dementia: An exploratory study of the first signs noted by carers and primary care practitioners

Michelle Bryans

A thesis submitted in part fulfilment of the requirements of the Degree of Doctorate in Clinical Psychology

University of Edinburgh

2006

Contents

Declaration

I declare that the work contained in this thesis is all my own.

Date: 18th May 2006

Acknowledgements

I would like to express my gratitude to the following people for their assistance and support: my thesis supervisors Jennifer Borthwick and Steve Turner for their endless patience, encouragement and guidance; Professor Murna Downs, Dr Steve Iliffe, Professor John Keady, Ms Enid Levin and Professor Ronan O'Carroll from the Alzheimer's Society Dykes Award study research team for their knowledge, support and assistance in developing my career and for allowing me to revisit the data; Jane Wilcock for her friendship, support and encouragement; my classmates for helping me see it through to end; and Terry for being there whenever I needed her most.

I'd like to say a huge personal thank you to my family and closest friends for their constant encouragement, patience and support, and for believing in me when I didn't believe in myself, especially my partner, my brother, my auntie Jean and my oldest friend Lorna.

In memory of my parents, Mary and Lawson.

Abstract

Dementia is a complex syndrome that poses challenges for the person with dementia, their family, and health and social care professionals. Primary care is often the first point of contact for people with dementia (Briggs & Askham, 1999), and primary care practitioners are recognised as having an integral role to play in the diagnosis and management of dementia (Downs, 1996). Around 70 per cent of people with dementia living in the community live with their carer. Most informal carers are the spouse or daughter of the person with dementia (Alzheimer's Scotland, 2000). Previous research has shown that caring for people with dementia can be stressful, although it also has many positive aspects, and that carers need support systems in place for themselves and their relative.

The aim of the current study was to explore the first reported signs of dementia by two groups known to be closely involved with individuals within the earlier stages of the condition, carers and primary care practitioners. Previously unanalysed data collected from carers and practitioners who participated in the Downs *et al* (2003) study "Improving the response of primary care practitioners to people with dementia and their families: A randomised controlled trial of educational interventions" was used.

A grounded theory approach (Strauss & Corbin, 1990) was adopted to explore the first signs of dementia reported by 122 carers and 204 primary care practitioners. Five main categories and thirty-two subcategories related to cognitive, emotional, behavioural, physical and other (non-categorised) signs of dementia were generated. Statistical analysis was carried out to explore the effect of sociodemographic and occupational variables on the first signs of dementia reported by carers and practitioners, and the effect of training on practitioner signs reported.

Findings were discussed and implications for clinical practice and future research considered.

1 Introduction

1.1 Models of dementia

Models for understanding dementia can be useful in developing an understanding of what dementia is and what it might mean for the person with dementia and their family. They can be a useful aid in the education of those caring for people with dementia, in that they can be used to illustrate different aspects of the syndrome. For example, psychosocial models highlight the importance of considering the whole person and their experience, not merely the disease process. Different models highlight different aspects of the syndrome, but regardless of the model adopted, it remains a fact that dementia is a syndrome with multiple physical, psychological and social dimensions. The complexity that it presents can pose challenges for the person with dementia, their family and the health and social care professionals who may be involved in supporting them.

Dementia, from a **biomedical** perspective, is defined as a complex syndrome characterised by the presence of a cluster of symptoms that meet current diagnostic criteria, given within DSM-IV as:

> "...the development of multiple cognitive deficits that include memory impairment and at least one of the following: aphasia; apraxia; agnosia; or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning"
>
> (American Psychiatric Association, 1994, p.138)

Differential diagnosis between differing causes of dementia, such as Alzheimer's disease and cerebrovascular disease, occurs following examination of the physical, neuropsychological and behavioural presentation of the individual. It is often a diagnosis of exclusion i.e. when all other known or treatable causes of such impairment are excluded, the diagnosis will be one of dementia. This definition implies that symptoms have a purely organic basis, and relies on a model of deficit. This in turn has implications for the way in which health care professionals view people with dementia, and for the treatment options they may be offered. It implies that the progression of dementia is unremitting and therefore its effects are outwith the control of the person or their significant others. The biomedical model is the most prevalent explanation within the developed world of the syndrome recognised as dementia, but is by no means the only explanation, and cannot explain the wide variations in presentation of symptoms between people with dementia who have similar patterns of cerebral damage.

The **disability model** takes as it's core rationale that dementia meets the criteria for a disability within the legally accepted definition of disability in the UK, which states that a disabled person is one who

> "has a physical or mental impairment that has a substantial long term adverse effect on his or her ability to carry out normal day to day activities"
>
> (Disability Discrimination Act, 1995)

Whilst dementia can be seen to fit within this definition, it goes no further than the medical model in explaining how individuals experience dementia. However, the

disability model has been extended to include the disabling effect that others can have on the functioning of a person with dementia. Barnett (2000) developed the idea of dementia as a **socially constructed disability**. Within this model, people with dementia are discriminated against by social prejudice, ageism and inaccessibility of services. These factors extend the level of disability a person with dementia may experience. From this perspective, intervention focuses on promoting social inclusion, breaking down barriers to inclusion, taking an individualised approach and empowering the disabled person to meet their maximum potential without being further disabled by society (Barnett, 2000).

Whilst the social disability model takes more account of the person with dementia and their experience of their world, it still focuses on what others 'do to' the person with dementia, rather than considering the interactional nature of their experience of the world.

Psychosocial perspectives shift the focus of interest from the medical to the experiential aspects of a person's journey through dementia. In their work on the personal experience of people with dementia, Cheston & Bender (2000) highlighted the importance of considering the individual's history, experiences, personal characteristics and social and cultural context. They found that the same cluster of medical symptoms may be experienced by different individuals in different ways, and will be affected by the individual's beliefs about their condition, the beliefs of those around them, the society they live in and their previous life experience.

A **biopsychosocial model** of dementia takes into account all aspects of a person's being, including their relationships with others. From this perspective, dementia is not merely the reflection of cerebral damage, but is a multifaceted expression of an individual's experience of their world and the relationships they have within in it. This model, proposed by Kitwood (1997), shifts the emphasis from a model of cognitive deficit to a model of social support, recognition of strengths as well as difficulties, respect for the person and investment in the quality of their interactions. Whilst the underlying disease process is not ignored, it is seen as being only one aspect of a person's experience.

Kitwood developed the idea of 'personhood' within dementia care, which he defined as

> "a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust"
>
> (Kitwood, 1997)

A biopsychosocial perspective places the person with dementia on an equal footing with those who wish to interact with him or her, and places the emphasis for change on the quality of the interaction between people, rather than on an outside entity, such as disease as in the biomedical model, or on society, as in the social disability model. Biopsychosocial interventions recognise that individuality and reciprocity are important factors in determining the quality of a person's interactions with the world. One recent study highlights the importance of considering the impact of biopsychosocial factors in dementia (Hall & O'Connor, 2004). In this review, the authors summarised some of the biopsychosocial contributions to the development of

aggressive behaviour in older people with dementia. Some of the important factors identified were: degree of cognitive impairment; personality; sensory change; physical illness; language impairment; brain pathology; affective state; and psychotic disorder. Hall & O'Connor (2004) also concluded that gender, sexuality, disruption of circadian rhythms and environmental factors were important in the development of aggressive behaviour. This study highlights the importance of viewing dementia as a multifaceted syndrome, affected by the interplay of biological, psychological and social factors.

Therefore, as can be seen, different models may highlight different aspects of the syndrome, but what is clear is that dementia is a syndrome with multiple physical, psychological and social dimensions. The complexity that it presents can pose challenges for the person with dementia, their family and the health and social care professionals involved in supporting them.

1.2 Prevalence and incidence of dementia

1.2.1 Prevalence

Prevalence is a measure of the frequency with which an event, illness or condition occurs in the population. Prevalence of dementia refers to the number of people with dementia in the population at a given point in time. A number of prevalence surveys have been carried out throughout the world (Hofman, Rocca, & Brayne, 1991; Jorm, Korten & Henderson, 1987). These tend to give slightly different results depending on the methods used in the study. However, all studies show a sharp rise in the

prevalence of dementia with age, and age is recognized as the main risk factor for the development of dementia. Jorm *et al* (1987) integrated prevalence data from Japan, America, Europe, Scandinavia and Australasia for a forty-year period between 1945 and 1985, and found that the relationship between prevalence and age was consistent across studies, with rates virtually doubling every 5.1 years. They also found that Alzheimer's disease was more common in women, with a tendency for multi-infarct dementia to be more common in men. The largest European prevalence study, from the EURODEM collaboration (Hofman *et al*, 1991), found that in subjects aged 75 years or below, the prevalence of dementia was slightly higher in men than in women, and in those aged 75 years or over the prevalence was higher in women. This study also found a significant increase in prevalence with age. Table 1 below highlights prevalence rates for each age group from these studies.

Table 1 - Age Specific Prevalence of Dementia (per cent) in people over 65

	Prevalence rate of dementia within each age band (per cent)	
	EURODEM (Hofman *et al*, 1991)	**Jorm *et al* (1987)**
Age band		
65-69	1.4	1.4
70-74	4.1	2.8
75-79	5.7	5.6
80-84	13.0	10.5
85-89	21.6	20.8
90-94	32.2	38.6
95-99	34.7	------

It is an important caveat that these figures were derived from surveys in more developed countries (Europe, North America, Australasia and Japan) and may not apply to less developed countries. The data available on prevalence in less well-developed countries is minimal, but what is available suggests that there may be differences in prevalence between the developed and developing world. Hendrie and colleagues used the same research methods to compare the age-adjusted prevalence of dementia in African Americans in Indianapolis (6.4 per cent) with Africans in Ibadan, Nigeria (1.2 per cent) (Hendrie, Osuntokun, Hall, Ogunniyi, Hui, Unverzagt, Gureje, Rodenberg, Baiyewu & Musick, 1995). Although prevalence rates of dementia and Alzheimer's disease increased consistently with advancing age in both study groups, there were significant differences in rates of dementia and Alzheimer's disease in the different communities, which reportedly had similar ethnic origins. Since the same research methods were employed at each site, methodological issues are less likely to have affected the result than in previous studies carried out in this area. Further research is needed to identify factors affecting prevalence rates in developing countries. Alzheimer's Disease International predict that in the developed countries of the world, dementia rates will increase from 7.4 million people worldwide in 1990 to approximately 10.2 million by the year 2010. It is also estimated that by 2025, 71 per cent of people with dementia will live in developing countries (Alzheimer's Disease International, 1999).

Since age is the main risk factor for the development of dementia, rates of dementia will be affected by predicted changes in the demographic profile of the population. The number of people with dementia in Europe is predicted to rise in proportion to the

rise in the number of older people within the population. The proportion of the European Economic Community population aged over 65 currently stands at 16.5 per cent, an increase of 2 per cent in the last 10 years. People aged over 80 accounted for 4 per cent of the total population in 2004 and this figure is expected to rise to over 20 per cent by the year 2050 (Eurostat, 2004). It has previously been estimated that 6.4 per cent of the over-65 age group in Europe were suffering from dementia (Lobo, Launer, Fratiglioni, Andersen, Di Carlo, Breteler, Copeland, Dartigues, Jagger, Martinez-Lage, Soininen & Hofman, 2000). If this percentage stays the same, and the number of people aged 65 and over goes up, then obviously the number of people with dementia will rise proportionately in Europe.

In the United Kingdom, the number of people with dementia has been estimated by the Alzheimer's Society using established prevalence rates and population numbers. Their figures show that dementia currently affects over 750,000 people across the UK, with over 18,000 of those people being aged below 65 years. It affects one person in 20 aged over 65 years and one person in five over 80 years of age. They predict that by 2010 there will be about 870,000 people with dementia in the UK, expected to rise to over 1.8 million people with dementia by 2050 (Alzheimer's Society, 1999).

At a local level, Alzheimer's Scotland estimates that there are at present around 63,000 people with dementia living in Scotland, of whom around 1,600 are under the age of 65. This estimate uses the General Register Office for Scotland's population figures for midyear 2002, EURODEM (Hofman *et al*, 1991) and Harvey (1998) prevalence figures.

1.2.2 Incidence

Incidence is a measure of the number of new cases of an event, illness or condition in a given time period. Incidence of dementia refers to the number of people with dementia in the population in a given time period.

An estimate of the incidence of dementia within the population is derivable from morbidity statistics within general practice. Each GP in the UK is estimated to have an average list size of 2000 patients (McCormick, Fleming & Charlton, 1995). The incidence rate of dementia in general practice is 1.6 new cases per GP per year (Eccles, Clarke, Livingston, Freemantle & Mason, 1998). A GP with an average list will see one or two new cases per year, and have up to 14 patients with dementia on their list at any one time. The average district nurse team with approximately 80 people on their caseload will have 5-15 people with dementia (Iliffe & Drennan, 2001). Extrapolating these figures using workforce planning statistics shows that in Scotland there will be, on average, just under 6,500 new cases of dementia identified each year, at an incidence rate of 1.6 per GP for 4,011 WTE GPs across Scotland in October 2004 (ISD Scotland, 2004). It is important that psychologists are aware of the incidence of dementia within general practice as this can affect the planning and provision of psychological services to older people. It is known that GP referral patterns to psychology vary depending on their knowledge and management of psychological problems, their ability to detect psychological problems and their links with mental health services (Ross & Hardy, 1999). It is therefore important that psychologists develop good referral patterns and good working relationships with

primary care if people with dementia and their families are to benefit from psychological input into the management of the condition.

1.3 Treatment and diagnostic issues in dementia

Diagnosis of a dementing disorder is generally based on the clinical and behavioural picture of the individual, and the elimination of other treatable conditions whose symptoms may mimic dementia, such as hypothyroidism, depression, hyperglycaemia, renal failure or hydrocephalus. It requires careful and rigorous assessment to rule out treatable causes and to formulate appropriate diagnostic and management strategies that will optimise the service the person with dementia receives from health care (Iliffe & Drennan, 2001). The increasing demands on the health care system posed by dementia, and the increasing numbers of people with dementia in the UK, have led to greater consideration of the complexities involved in caring for people with dementia and a greater interest in their needs. The earlier diagnosis of dementia has become the subject of much research and comment in recent years. Some of the reasons for this include the development of pharmacological therapies for dementia (Arrieta & Rodriguez, 1988; Department of Health, 1997) and the development of psychological interventions (Clare, Wilson, Carter, Breen, Gosses & Hodges, 2000). Dementia has also become a political issue to a greater degree. The Department of Health in the UK has made older people and mental health a political issue with the publication of a National Service Framework for Older People (Department of Health, 2001). This has meant that the ability of health care practitioners to respond to the needs of people with dementia and their families has come under greater scrutiny (Eccles *et al*, 1998).

1.3.1 Treatment considerations

One reason for the raised level of interest in the earlier diagnosis of dementia is the advent of the "anti-dementia drugs", or acetylcholinesterase inhibitors. These drugs were developed following the discovery that Alzheimer's disease causes neuronal death, particularly in the forebrain and cerebral cortex, leading to depletion in the number of cholinergic neurons (Goedert, 1993). This leads to a reduction in the amount of the neurotransmitter acetylcholine available in the brain. Cholinergic deficits are thought to contribute to the deterioration in memory and other cognitive functions experienced by people with Alzheimer's disease (Bartus, Dean, Beer, & Lippa, 1982). Acetylcholine is synthesised within a cholinergic synapse by the reaction between choline and acetyl-coenzyme A. It is then released into the synaptic cleft, where it can bind to receptors on the post-synaptic cell. Once it has dissociated from these receptors, it is inactivated by the enzyme acetylcholinesterase (Beatty, 1995). Acetylcholinesterase inhibitors act by preventing the breakdown of acetylcholine within the synaptic cleft, leading to an increase in the amount of acetylcholine available to bond with cholinergic receptors within the brain. The intended outcome of this inhibition is improvement in the cognitive functioning of individuals with Alzheimer's disease, or maintenance of a stable level of functioning over a longer period of time (Eager, 1996).

The use of these drugs has been controversial since their introduction. Initial trials of tacrine, the first such drug to be licenced for use in Alzheimer's disease, concluded that 30-55 per cent of patients would benefit. However, in a review of 49 clinical trials of the drug, Arrieta & Rodriguez (1998) stated that it showed "only a modest degree

of efficacy in a small proportion of patients with mild to moderate Alzheimer's disease". Arrieta and Rodriguez (1998) noted, of the 3555 patients enrolled in the trials they reviewed, 1149 patients did not complete the trial, and that 80% of those who did not complete withdrew due to adverse effects from tacrine. Adverse effects included cholinergic manifestations outside the brain, mainly nausea and gastrointestinal upsets (mean 30.2 per cent across all trials) and raised liver enzymes causing liver dysfunction (mean 28.6 per cent across all trials). Tacrine's poor safety profile has led to its withdrawal as a treatment for Alzheimer's disease in the United States, and it has not been licenced for use in most European states (Qizilbash, Whitehead, Higgins, Wilcock, Schneider, & Farlow, 1998). More recent developments include the introduction of the drugs donepezil, rivastigmine and galantamine, all acetylcholinesterase inhibitors, but all with a better safety profile than tacrine (McRae, Relkin & Knopman, 1998; Rosler, 1999; Tariot, 2000).

The National Institute for Clinical Excellence (NICE) reviewed these drugs in the UK and issued guidance for their use in clinical practice (NICE, 2001). NICE advised that these drugs should be available to people with mild to moderate Alzheimer's disease, after assessment by a specialist, and under strict prescribing rules. This guidance stated that early diagnosis of Alzheimer's disease was an important outcome for people with the disease, since treatment was optimised in the early stages, and treatment was not to be considered for patients in the more severe stages of the disease, thus placing a responsibility on health and social care practitioners involved in the earlier detection of the disease. A further review planned for 2003 has since

been widened due to the rapid advances in treatment options, and is currently out for consultation (NICE, 2004).

This consultation document has caused controversy in that it concludes that the anti-dementia drugs should not be used routinely in clinical practice, as they are not cost-effective. The Alzheimer's Society responded immediately, demanding that people with dementia be given access to these drugs, which they claim have made a huge difference to the lives of people with dementia (Alzheimer's Society, 2005). Following a meeting with the Alzheimer's Society to discuss their concerns, the government released a press statement indicating that there appeared to be many issues not taken into account by NICE in their appraisal, such as possible benefits to carers in terms of less time spent in caring; longer time at home for people with dementia; and the use of drugs such as anti-psychotics to treat cognitive and behavioural issues in dementia (Department of Health, 2005). The debate continues as to whether these drugs will be prescribed in the NHS and a response is expected from NICE shortly.

The anti-dementia drugs are, however, just one of the possible therapeutic options for people with dementia. Psychological therapies offer a non-invasive, non-pharmaceutical, person-centred approach to dealing with the cognitive, social and behavioural difficulties people with dementia may experience. There is increasing evidence that psychological approaches can help in the management of sleep difficulties in dementia (McCurry *et al*, 2003), in the management of depression in people with dementia (Teri & Gallagher-Thompson, 1991) and in the management of

behavioural difficulties in residential settings for older people (Teri *et al*, 2005). Although there is an increasing body of research evaluating the efficacy of such approaches, particularly in the early stages of dementia, access to psychological therapies is unevenly distributed throughout the country due to the small number of psychologists working with older adults. The issue of earlier diagnosis is pertinent for psychologists working with people with dementia, not only in their role as neuropsychological assessors, but also in their choice and delivery of therapy and in determining which approaches are open to them.

Problems with memory are one of the main problems experienced by people with Alzheimer's disease in its early stages (Brandt, 1995) and also arise in the early stages of vascular dementia. These difficulties can have a detrimental affect on self-confidence and can lead to anxiety, depression and withdrawal from activities. This can make memory difficulties seem worse, and therefore help with memory problems in the early stages of dementia may be very important (Clare, Woods, Moniz-Cook, Orrell & Spector, 2005). Interventions reported in the literature as effective in early stage dementia include cognitive training and cognitive rehabilitation.

Unlike healthy older people, those with Alzheimer's do not respond to comprehensive memory enhancement programmes (Mohs, Ashman, Jantzen, Albert, Brandt, Gordon, Rasmusson, Grossman, Jacobs & Stern, 1998). However, memory can be improved for specific tasks through training, support, and manipulation of environmental cues. Improvement is particularly powerful if the training focuses on relatively preserved skills (Bäckman, 1996). Cognitive training is based on the assumption that practice on

a task will improve or maintain functioning in the cognitive domain tested by that task. It has been assumed that any improvement will be generalized across other cognitive domains, although this has not been observed in the majority of studies (Clare *et al*, 2005). The main functions normally tested are memory and executive functions, such as attention, planning and problem solving. A number of studies have attempted to demonstrate efficacy of cognitive training, across a range of situations.

One study of individual training (Davis, Massman & Doody, 2001) tested the efficacy of training participants in making face-name associations. During the intervention, people with Alzheimer's disease showed a small but significant improvement in recall of personal information, face-name recall, and performance on a measure of attention. However, this improvement did not generalise to other cognitive domains and measures of quality of life showed no improvement. It is difficult to ascertain though, whether there was any true effect on quality of life in this study since this was measured indirectly using a caregiver assessed measure, rather than a subjective assessment with the person with dementia.

Cognitive training in specific activities of daily living has been shown to be effective in improving performance in the area of procedural memory, that is knowing 'how to do' a task (Farina, Fioravanti, Chiavari, Imbornone, Alberoni, Pomati, Pinardi, Pignatti & Mariani, 2002). However, improvements in this study were found to be short-lived and measures had returned to pre-training levels by 3-month follow-up. Whilst this may seem a short space of time, it must be remembered that the needs of the person with dementia will change as the disease progresses and it may be

necessary to 'top-up' training intermittently to meet the person's needs and changing level of ability. The need for 'top-up' therapy is not uncommon in psychology across different age groups, conditions and therapies and it should not be seen as a treatment failure if gains are not held by the person with dementia.

Group training programmes have demonstrated some benefit from cognitive training. One study of 25 older people with mild to moderate dementia, matched against an age-matched control group, found a small but significant improvement in name-face recall and lowered scores on a measure of depression in participants following a 5-week training programme, and maintenance of these benefits at follow-up a month later (Moore, Sandman, McGrady & Kesslak, 2001). Again, time to follow-up is short and there was no significant difference on measures of quality of life or behavioural rating scales.

Cognitive rehabilitation is an individualised approach to helping people with cognitive impairment. The emphasis is on improving functioning in the areas of everyday functioning that those affected, and their families, identify as personally relevant goals. They are assisted by health professionals to devise strategies to meet these goals, in collaboration with their significant others (Wilson, 2002). There is no expectation that gains will be generalised across other cognitive domains, and goals may change throughout the course of therapy. Cognitive rehabilitation has been shown to be effective in small numbers of people with early Alzheimer's disease, and in single case studies (Clare, Wilson, Breen & Hodges, 1999; Clare, Wilson, Carter, Gosses, Breen & Hodges, 2000; Clare, Wilson, Carter, Hodges & Adams, 2001).

Whilst the literature reports many individual studies that have demonstrated significant results using these interventions, independent reviews have not arrived at a consensus as to their efficacy. One comprehensive review concluded that cognitive training interventions are 'probably efficacious' in slowing decline in dementia (Gatz, Fiske, Fox, Kaskie, Kasi-Godley, McCallum & Wetherell, 1998), but stated that further work needed to be carried out, particularly high quality randomised controlled trials, to overcome methodological problems in studies to date. The most recent review (Clare *et al*, 2005) concluded that these interventions may sometimes produce modest benefits in certain domains of cognitive functioning, but that findings did not provide strong support for the use of cognitive training, although the studies reviewed had methodological difficulties and small participant numbers. The authors also concluded that it was not possible to draw any firm conclusions about the use of cognitive rehabilitation for people with early stage dementia. Since there were no randomised controlled trials as yet of this intervention, Clare *et al* (2000) recommended that further research was needed to fully evaluate the efficacy of this approach.

The evidence for psychological interventions such as cognitive training and rehabilitation appears to be limited at present by the amount and quality of research carried out, although what has been presented shows positive outcomes from both interventions. For further research to be carried out, participants in the early stages of dementia must be available for inclusion and willing to take part in research, thereby necessitating early detection and identification of dementia. Further research is clearly

necessary and it is therefore very important to be able to detect dementia in its earliest stages. Advances in psychological intervention, drug treatment and effective carer support are reliant on the continuation of research in these areas.

1.3.2 Diagnostic considerations for people with dementia and their family

Arguably the most important evidence for the benefits of earlier diagnosis comes from the literature on what people with dementia and their significant others want. There is much more to receiving a diagnosis than deciding what psychological or pharmaceutical therapies are appropriate and desired by people with dementia. For many, diagnosis gives them a chance to put their affairs in order, ask questions about their illness and prognosis, sort out financial concerns, go through a period of adjustment, and develop coping strategies, whilst at a stage of their illness where their cognitive capacity permits this. Others do not wish to know their diagnosis and this wish must be ascertained and then respected by health care professionals.

Erde, Nadal & Scholl (1988) examined the wishes of older people relating to receiving a diagnosis of dementia. They asked patients aged 65 and over attending two GP practices to read a vignette of a person with Alzheimer's disease and decide, if they were that person, whether they would wish to be told about their diagnosis. Ninety-two per cent of respondents stated that they would wish to be told about their diagnosis by their doctor, and 87 per cent stated that the person's nearest relative should be told the diagnosis (Erde, Nadal & Scholl, 1988). The respondents in the

study by Erde *et al* (1988) were not cognitively impaired and were commenting on a hypothetical situation in which they were asked to imagine themselves as having dementia. It could be argued that the unreality of the situation would affect the outcome of the study, and that, when faced with the reality of having dementia, opinions may change. Marzanski (2000) sought to address this issue by asking people with dementia what they would like to be told about their illness (Marzanski, 2000). Seventy per cent of participants in this study, all of whom had dementia, stated that they would like to know more about their illness. Marzanski (2000) found that the quality of information participants had received was poor, and that the majority of participants had not had the chance to discuss their illness with anyone. The importance of discussing the individual's preference for receiving information is a major outcome of this study. Thirty per cent of participants in this study either did not wish to know more about their condition or were unsure if they wanted more information. Marzanski (2000) highlights the importance of eliciting a patient's preference for knowing more about their condition before entering into discussion about prognosis, since some patients will make the choice not to know what is wrong with them.

Previous research with carers of people with dementia has shown differences in their preference for being given a diagnosis depending on whether it has already been received. Maguire, Kirby, Coen, Coakley, Lawlor & O'Neill (1996), in their study of 100 family caregivers where the relative was aware of diagnosis but the patient was not, found that 17 per cent of participants said that the patient should be told the diagnosis, whilst 83 per cent said they should not. The main reason given for non-

disclosure was that the diagnosis would upset or depress the patient. However, 71 per cent said that they would want to know their diagnosis if they developed Alzheimer's disease. Maguire *et al* (1996) concluded that this inconsistency might be due to generational differences in the perception of dementia, the desire of family members to protect patients from the truth about their illness, and family members' reluctance to deal with the patient's knowledge of their diagnosis and possible grief resulting from this (Maguire *et al*, 1996).

Once the diagnosis of dementia has been given, the perception of how useful it is appears to change. Smith, King, Hindley, Barnetson, Barton & Jobst (1998) looked at this issue in a study of 79 family carers and found that the majority (98 per cent) reported that giving a diagnosis had been helpful for them, and 84 per cent reported that it had been useful for their relative with dementia. Smith *et al* (1988) concluded that patients and families could benefit from early disclosure of diagnosis, but that to obtain this, early referral to specialist services was necessary. Smith *et al* (1988) highlighted the need for sensitive and ongoing support for people with dementia and their families, and concluded that further research into patients' reactions to diagnosis was indicated (Smith *et al,* 1998).

The concerns raised by carers in a number of studies such as those previously outlined relate to their reluctance to cause distress to the person with dementia. Recent work demonstrates that their concerns might be misplaced and that giving the diagnosis can be more helpful than not. Pinner & Bouman (2003) followed up 50 people with mild dementia for one year and found that the majority (92 per cent) wished to be informed

of their diagnosis. Ninety-eight per cent of carers would wish to be told if they were to develop either dementia or cancer. Eighty-eight per cent of patients and 86 per cent of carers would make use of a predictive test for Alzheimer's disease, were one available, and all patients and carers would like access to treatment for dementia. Before receiving their diagnosis, only 28 per cent of patients thought that they might have dementia. After 1 year, only 6 per cent of those who had been given their diagnosis in the original sample had developed a depressive illness requiring antidepressant treatment and no major incidents e.g. suicide, had occurred following disclosure of diagnosis. Therefore the fears of many carers, and health care professionals, about giving the diagnosis may be unfounded. This study also further highlights that early detection is important for some people with dementia.

1.3.3 Diagnostic considerations for health care practitioners

Research to date appears to indicate that, in the majority of cases, early diagnosis is desired both by people with dementia, and by their carers. However, access to an early diagnosis remains difficult for many people due to factors relating to the health care practitioners with whom they have contact. Many researchers in the field, in relation to differing professions, have considered this issue.

Keightley & Mitchell (2004) used a grounded theory approach to elicit the views of community psychiatric nurses and clinical psychologists about disclosure of diagnosis (Keightley & Mitchell, 2004). The main influence on disclosure practice was uncertainty about whether the person with dementia wanted to know their diagnosis.

Participants reported fear of causing harm to the patient if diagnosis was disclosed when they had not wanted to know, and expressed hopelessness and helplessness when dealing with dementia. It would appear that more open lines of communication and greater involvement of the person with dementia, at all stages in the diagnostic process, are required to help professionals resolve their uncertainty about what the person with dementia wants.

A survey of old age psychiatrists showed that their delivery of information depended on the severity of the person's dementia (Rice & Warner, 1994), with 38 per cent of respondents saying they "nearly always" informed patients with mild dementia about their illness, but only 13 per cent of people with moderate dementia and 6 per cent of people with severe dementia. However, 98 per cent stated that they "nearly always" informed carers of the diagnosis. Surprisingly, prognosis was rarely discussed with either group. The decision on whether to give information appeared to depend on what the old age psychiatrist deemed was the person's cognitive capacity to understand the information given. Therefore, the earlier the person is diagnosed by specialist services, the greater the likelihood they would be told their diagnosis.

Rice & Warner (1997) compared their findings from an old age psychiatrist population with 138 geriatricians who had experience of giving the diagnosis of dementia. They found that practice varied widely, although in general, patients with mild dementia were told more about their illness and given their diagnosis more frequently than those with moderate or severe dementia. Seventy-five per cent of respondents reported informing over 80 per cent of carers of their relatives' diagnosis.

Results were similar to those obtained in the psychiatrist population, although the geriatricians told patients their diagnosis more often, and carers less often, than did the psychiatrists. Rice & Warner (1997) concluded that carers should not usually be given information that cannot also be given to the patient, and that exchange of information should be patient led, when the patient is mildly demented. They do not comment on what practice should be when the person is in the moderate or severe stages of dementia.

There appears to be a 'therapeutic nihilism' related to the conceptualisation, diagnosis and management of dementia (Iliffe & Drennan, 2001; Graham, 1995; Wolff, Woods & Reid, 1995). Wolff *et al* (1995) found in a study of general practitioners that GPs felt they had little to offer patients with dementia, that early referral, and therefore the possibility of earlier diagnosis, was unhelpful, that dementia was mainly a social problem and that easier access to long-term care was required. Graham (1995) found that 70 per cent of GPs in her study had great difficulty in conceptualising dementia as a diagnosis. Iliffe & Drennan (2001) report that the complexity of dementia as a syndrome causes particular problems for GPs, and that this can cause delays in the person with dementia receiving a diagnosis, as GPs are often the first point of contact for people with health concerns.

1.4 The role of primary care in dementia

Primary care remains the first point of contact for people concerned with their own health needs, including poor memory performance, and is often the first point of

contact for people with dementia (Briggs & Askham, 1999). The primary care team have a central role to play in the earlier detection, identification, diagnosis and management of dementia and act as the gatekeeper to specialist services, as well as having an integral role providing ongoing support for people with dementia and their carers (Downs, 1996).

The incidence of dementia within general practice is low in comparison to other major health issues (Iliffe & Drennan, 2001). However, the workload for primary care associated with the care of people with dementia is disproportionate to the number of cases per practice. Among adults, the proportion of GP consultations that take place in the home increases with age. In 2003/04, 2 per cent of consultations for 16 to 44 year olds for all conditions were in the home, compared to 11 per cent of consultations for those aged 75 and over (Office for National Statistics, 2005). For people with dementia, the home visiting rate for people over 75 has been estimated at around 71 per cent (Eccles *et al*, 1998), and they require consultation with their GP approximately twice as often as older people without dementia. Therefore, incidence of the disease is not a good predictor of the service required by people with dementia from primary care services. The reasons for this are complex and relate not only to the nature of the disease, but also to the widespread effects on family, the community and services; the historical view of dementia; the increase in availability of, and research into, psychological treatment options; and the advances in pharmaceutical treatment options available within the last decade.

Not surprisingly, given the factors discussed earlier, early detection of dementia has gained increasing recognition as a benchmark of good practice (Audit Commission, 2000, 2002; Department of Health, 2001) The importance of the role of primary care, especially in the early stages of dementia, was outlined by the Audit Commission in their report on mental health services for older people (2000) as follows:

- The primary care team often have contact over many years with patients and their families, and are well placed to monitor changes in presentation
- They are usually the first professionals with whom patients and their relatives discuss new health concerns
- GPs can make referrals to specialists, carry out initial assessments and investigations, and help to rule out treatable causes of symptoms
- They can provide advice and support, and prescribe medication if necessary
- They have an important role to play in monitoring progress and providing physical health care and psychological support for the person with dementia and their carers.

(Audit Commission, 2000)

More recent reports have highlighted the importance of placing greater emphasis on promoting good health across the lifespan, rather than on episodic care (Audit Commission, 2004). Primary care teams are well placed to deliver this aspect of service provision given their long-term contact with patients, and their statutory obligation to provide preventative health care, screening and health promotion initiatives. This shift in emphasis would benefit people with dementia and their carers

as the onset of dementia is generally insidious and change usually occurs gradually. Primary care teams are also ideally placed to advise patients about the risk factors for certain types of dementia, such as the increased risk of cerebrovascular changes if they are overweight, smoke, have high blood pressure or a high fat diet.

As discussed earlier, research has shown that primary care practitioners have difficulty with the early recognition of dementia and in providing subsequent support for those affected (Eccles *et al*, 1998; Downs, 1996; McIntosh *et al*, 1999; Iliffe, 1997). These difficulties arise due to a range of factors including the low incidence of dementia in general practice, the perception of symptoms by the person or their carer, social and cultural factors, lack of knowledge among practitioners' and the relative lack of treatment options for dementia (Iliffe, 1997).

Since 1989, GPs have been contractually obliged to offer an annual health assessment, including mental state, to people aged 75 and over (Department of Health, 1989). This task has increasingly been shared among the primary care team and carried out by practice nurses, district nurses and health visitors, as well as GPs (Pritchard and Dewing, 1999). Mental health screening within this assessment could be an opportunity to detect the early signs of dementia, but evidence suggests that primary care nurses feel that they have little relevant training or experience pertinent to this role (Chew, Wilkin & Glendinning, 1994; Ford, Middleton, Palmer & Farrington, 1997; Secker, Pidd and Parham, 1999). Practice nurses have reported that they feel unprepared to deal with psychological problems, including dementia, and are reluctant to get too involved with clients in case they uncover problems they cannot cope with.

They identified their main problems as lack of access to appropriate educational support and poor inter-professional relationships with mental health personnel (Nolan, Murray & Dallender, 1999).

In one study involving primary care nurses (Trickey, Turton, Harvey, Wilcock & Sharp, 2000), only one-fifth of respondents used any type of formal cognitive screening tests in routine practice. There was wide variation in what nurses saw as their remit in identifying suspected dementia, with 10 per cent taking no action at all if they suspected dementia.

Research involving GPs shows that they also feel unprepared for dealing with the challenges dementia poses. The Alzheimer's Society (1995a), in a study of general practitioners, reported that 71 per cent felt that they had insufficient training in management of dementia and had poor awareness of support services available (Alzheimer's Society, 1995a). These findings were echoed in a recent study of GPs (Downs, Cook, Rae & Collins, 2000), and respondents once again noted the issue of insufficient training as a major influence on practice. Downs *et al* (2000) noted that GPs self-reported responses to the diagnosis and management of dementia was not consistent with recommended practice from published guidelines (Alzheimer's Society, 1995b; Eccles *et al*, 1998; Scottish Intercollegiate Guidelines Network, 1998), and that they perceived dementia as a difficult condition to both diagnose and manage, particularly in the early stages.

Another major issue in the area of dementia care in primary care concerns the introduction of formal guidelines to assist in the identification process. Few of the respondents in the Trickey *et al* (2000) sample were aware of the existence of guidelines published by the Alzheimer's Society (1995b), despite these guidelines having been issued as part of a national campaign by the Alzheimer's Society to provide guidance on management strategies for dementia in general practice.

The publication of guidelines by the Alzheimer's Society in 1995 were augmented by the production of the North of England Evidence-Based Guidelines (1998) on the primary care management of dementia, developed to provide a framework for effective clinical practice in dementia care. At a local level, the Scottish Intercollegiate Guidelines Network have produced recommendations for good practice in the management of behavioural and psychological aspects of dementia (SIGN, 1998) and in the management of patients with dementia (SIGN, 2006), which includes recommendations on management of cognitive aspects of dementia not considered in the 1998 SIGN guidelines. However, it appears the formulation and dissemination of guidelines alone is insufficient to ensure that the service received by people with dementia and their carers is optimised (Downs *et al*, 2003).

McIntosh, Swanson, Power & Rae (1999) highlighted some of the possible reasons why the development of guidelines alone may be inadequate to change professional practice. They found that primary care practitioners not only perceived dementia as a 'difficult condition' to treat medically, they also found it stressful, and expressed uncertainty about their roles in relation to its management and in working with people

with dementia and their families. Respondents commonly expressed feelings of helplessness and anxiety in relation to managing dementia. McIntosh *et al* (1999) advocated training in the social management of dementia, as well as in its technical and diagnostic elements, and concluded that the attitudes and anxieties of professionals need to be identified and explored if people with dementia and their families are to receive an optimal service. Other barriers identified which affect the implementation of guidelines in clinical practice include; lack of awareness of guidelines, unwillingness to accept diagnosis and management of dementia as part of the role of primary care; and reticence to provide what practitioners consider to be a 'heartsink' diagnosis i.e. one with few perceived treatment options (Bryans & Wilcock, 2001).

The lack of appropriate training for primary health care practitioners is a recurring theme in the debate about how to optimise care for older people with dementia, and practitioners have consistently reported that they felt they did not have the appropriate knowledge or skills regarding the diagnosis and management of dementia, and were anxious in relation to their role in dealing with this condition (Alzheimer's Society, 1995a; Bryans & Wilcock, 2001; Chew *et al.* 1994; Downs *et al.* 2000; Downs *et al*, 2003; Ford *et al.* 1997; Iliffe, 1997; McIntosh *et al*, 1999; Nolan *et al.* 1999; Secker *et al.* 1999; Trickey *et al.* 2000).

The implications of unprepared and under confident practitioners for people with dementia and their families include a lack of choice regarding treatment, a lack of control over their decisions and delays in the delivery of vital support services

(Bryans, Keady, Turner, Wilcock, Downs & Iliffe, 2003). More positively, the research to date also implies that increasing the knowledge and skills of practitioners could potentially help to resolve practitioners' difficulties in diagnosis and management of the condition, and improve the service received by people with dementia and their families (Downs *et al.* 2003; Turner *et al.* 2004).

1.5 The role of family carers in dementia

Over 60 per cent of people with dementia live at home, and around 70 per cent of people with dementia living in the community live with their carer. Most informal carers are the spouse or daughter of the person with dementia, often supported by a range of community and health care services (Alzheimer's Scotland, 2000).

Previous research has shown that caring for people with dementia can be an arduous task (although it also has many positive aspects) and that carers need support systems in place for themselves as well as for their relative. Coope, Ballard, Saad, Patel, Bentham, Bannister, Graham & Wilcock (1995) carried out a study with 125 patients with dementia, of whom 109 had family members or friends as the main carer. Twenty-eight per cent of the carers reported symptoms that met diagnostic criteria for depression, and almost 3 per cent reported diagnostic level symptoms of anxiety. In addition, 33 per cent of carers reported symptoms that were subclinical. First-degree relatives were more likely to suffer from depression than friends or more distant relatives. In a follow up to this study, the same group of carers was tracked for one year (Ballard, Eastwood, Gahir & Wilcock, 1996) to gain an insight into the length

and determinants of depression in this group. The incidence of depression lasting one month or more was 25 per cent, three months or more was 25 per cent, and 30 per cent of carers reported clinical depression for the whole year of follow up. The average overall was five months. The most significant factors associated with the number of months of depression were living with a dementia sufferer, depression in the person with dementia and problem behaviours such as aggression.

It appears that caring in itself is not the only significant factor in understanding the stress and psychological problems experienced by carers of people with dementia. Gonzalez-Salvador, Arango, Lyketsos & Barba (1999) compared carers of people with Alzheimer's disease and those who cared for older people without dementia. Spouses, followed by adult children, were most likely to care for the person in both groups. Those who cared for a relative with dementia had higher scores on measures of stress and psychological morbidity than carers of non-dementing relatives. Behavioural symptoms were associated with higher levels of caregiver stress. Length of care was associated with higher scores on measures of caregiver psychological morbidity. Therefore, interventions aimed at reducing stress and caregiver morbidity may best be targeted at helping them to understand and manage the behavioural sequelae of dementia (Coon *et al*, 2003; Gallagher-Thompson & DeVries, 1994).

Physical well-being can also be affected by caring for a person with dementia. Argimon, Limon, Vila & Cabezas (2004) matched a sample of carers and non-carers from the general population for age and gender, and measured their health status. Females in the carer group scored significantly lower on measures of mental health

and wellbeing, and higher on measures of bodily pain they experienced daily and their perceived emotional investment in caring, than did their age-matched contemporaries. The authors concluded that female carers of people with dementia experience a significantly decreased quality of life compared to non-caring females.

Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, (1991) demonstrated in a longitudinal study that spousal carers of people with dementia have lowered rates of immunity and higher rates of infectious diseases than age-matched controls.

In a study of 50 spousal carers of people with dementia, mean scores on the Global Measure of Perceived Stress scale were significantly higher in carers than in controls (Vedhara, Cox, Wilcock, Perks, Hunt, Anderson, Lightman & Shanks, 1999). In this study, salivary cortisol concentrations were measured over a single day at three time points (0800–1000, 1100–1300, and 2000–2200). Concentrations were higher in carers than controls at all three assessments (salivary cortisol concentration increases in response to stress). The carers' response to an administered influenza vaccine was also measured at 7-day intervals, and results showed a poor antibody response to the vaccine. Therefore, older carers may be more vulnerable to infectious disease than a non-caregiver population of a similar age.

Nonetheless, the literature also reports on positive aspects of caring. Providing the best care they can give has been identified as a source of satisfaction among carers, and this is derived from three main areas: the interpersonal dynamic between the

caregiver and the person being cared for; the intrapersonal world of the caregiver; and the desire to promote a positive outcome, or avoid distress, for the person being cared for (Grant & Nolan, 1993). Maintaining the dignity and self-esteem of their relative has also been cited as a major source of satisfaction for many carers.

Satisfaction with caregiving and a reciprocal relationship with the person being cared for have been shown to act as a buffer against negative stress (Lundh, 1999). Andren & Elmstah (2005) found in a study of 153 family caregivers that one or more sources of satisfaction were highlighted by carers on the Carers' Assessment of Satisfaction Index, regardless of the degree of burden reported by the carer on the Caregiver Burden Scale. Therefore, burden and satisfaction can co-exist. It is important for health and social care professionals to take this into account when offering support, as it highlights the complex and reciprocal nature of caregiving relationships when the person being cared for has dementia.

1.6 Meeting the needs of people with dementia and their carers

Many carers have reported that their relative was diagnosed late in the condition and often following a crisis (Audit Commission, 2000, 2002); what Twigg & Atkin (1994) refer to as a 'reactive model' of support. This reactive model denies people with dementia and their families access to assessment and treatment that could improve their quality of life, functioning and psychological and physical wellbeing. It can clearly be seen that people with dementia and their carers have complex needs that must be considered if services are to be fully responsive, flexible and well placed to

offer an optimal service. A recent report on the health needs of older people with mental health problems stated that:

> "...The best care for them (older people) can be achieved when Community Mental Health Teams for older people and primary care work together and with other agencies to deliver earlier diagnosis, followed by treatment and support tailored to individual circumstances and changing needs... Good joint working will support individuals and their carers, minimise the need for patients to go into hospital, and will provide patients and carers with practical and continuing help. Carers themselves are entitled to expect support, and carers' groups can be highly effective: providing local networks, sharing problems and feelings, and sharing skills and knowledge, too.
>
> (ADDING LIFE TO YEARS, Scottish Executive, 2002)

This report also made recommendations based on best practice in the field. These included: raising awareness of older people's mental health issues, and promoting early stage recognition and treatment of problems; assessing population needs for mental health services and planning appropriate capacity; and ensuring services are available to provide rapid assessment of cognitive impairment, with appropriate access to drug treatment and follow up.

These sentiments have been echoed in other statutory documents. The Framework for Mental Health Services in Scotland states that:

> "local and regional approaches to service planning for dementia diagnosis, care and support should be based on ongoing assessments of incidence and prevalence of dementia"
>
> (The Scottish Office, 1997)

This document also highlights the need for age appropriate responses to younger people with dementia, and states:

> "the importance of support for the carers of people with dementia throughout the course of the illness must not be underestimated".
>
> (The Scottish Office, 1997)

The UK government has recognized that carers need information, support and care for themselves (Department of Health, 1999a) and Standard 7 of The National Service Framework for Older People states as one of its aims that:

> "Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support, for them and for their carers".
>
> (Department of Health, 2001)

The fact that the government has said the above is indicative of their recognition that the response to the needs of people with dementia and their carers is sub-optimal. Government strategies have been outlined to address the issues of poor service provision, unresponsive services, carers' needs and earlier access to diagnosis and services. An integral service within this thrust for change is primary care.

1.7 Improving the response of primary care to people with dementia

The need for further research on dementia in primary care has been highlighted as essential if practitioners are to be enabled to recognise and use clinical signs and symptoms to estimate prognosis and select appropriate clinical strategies. This is crucial to understanding and improving care for this patient group, and for the development of new diagnostic tools and therapeutic interventions (Woods, Moniz-Cook, Iliffe, Campion, Vernooij-Dassen, Zanetti & Franco, 2003). One of the major

themes to emerge from the research with primary care practitioners is the need for appropriate training.

Downs, Turner, Iliffe, Bryans, Wilcock, Keady, Levin & O'Carroll (2003), set out to investigate whether training could improve the response of primary care practitioners to people with dementia and their families. This three-year multi-centre, randomised controlled trial was funded by the Alzheimer's Society. Downs *et al* (2003) developed and tested the differential effectiveness of three formats of an educational intervention within primary care. Thirty-five primary care practices were recruited from two health authorities in London and two Health Board areas in Central Scotland, giving a mix of urban and rural practices. Practices were randomly assigned to one of three training groups or to a control group who received no intervention. The training interventions developed were: a small practice-based workshop program; a CD-Rom covering the same material; and a Decision Support Software package which guided practitioners through different types of consultation relating to dementia. Interventions were developed in line with best practice in the field of dementia diagnosis and management in primary care, as outlined in the North of England Evidence Based Guidelines on the primary care management of dementia (North of England Evidence-based Guideline Development Project, 1998).

Recruitment within practices yielded a study population of 126 general practitioners, 78 nurses, 161 carers of people with dementia (122 at pre-intervention stage and 39 new carers post-intervention), and 450 medical records for analysis. One hundred and twenty-two carers took part in a semi-structured interview pre- and post-intervention,

or in the case of carers from control practices, at least 9 months from the date of their first interview. This interview included pre-coded and open questions about their relative's journey through dementia from pre-diagnosis to the present time. Sociodemographic information was gathered on the person with dementia and the carer. Carers rated practices on a number of factors including satisfaction with response to first concerns, satisfaction with service, helpfulness of practitioners, helpfulness of information and support they had received. They also completed measures of unmet need, knowledge of services and knowledge of dementia. Thirty-nine carers of people diagnosed with dementia since the intervention was delivered to their primary care practice took part in the same interview post-intervention. Practitioners completed a questionnaire on knowledge, diagnosis and management of dementia pre- and post-intervention. Medical records of all people with dementia for whom permission was obtained following ethical guidelines, with or without a family carer, were examined using a proforma developed and piloted by the study team, and based on good practice guidelines.

The main outcome measure for the study was concordance with guidelines, as measured by evidence of change in diagnostic or management practice through analysis of medical records. Additional outcome measures included rates of diagnosis, practitioner knowledge, carer knowledge of dementia and available services, and carer satisfaction with primary care. Results of this study showed:

- Statistically significantly improved practitioner knowledge in those who used the CD-Rom as compared to controls

- Statistically significantly improved rates of diagnosis in practices who had used Decision Support Software (DSS) as compared to controls

- No significant difference in concordance with clinical guidelines regarding diagnosis or management between practices who had received an intervention and controls

- No significant change in carer knowledge about dementia, knowledge and use of services, satisfaction with primary care or carer stress between those carers in intervention practices and those in control practices.

The main conclusion drawn from the study was that there are effective ways of improving knowledge about dementia and improving diagnostic rates in primary care in relation to dementia. It was suggested that future research into using combined interventions within practices rather than isolated interventions be considered, and that qualitative approaches should be considered to evaluate the effectiveness of interventions. This type of approach would also contribute to understanding of what is important to people with dementia, their families and practitioners. Details of the study design are reported elsewhere (Iliffe, Wilcock, Downs, Turner & Bryans, 2002a), as are the educational interventions (Iliffe, Wilcock, Austin, Walters, Rait, Turner, Bryans & Downs, 2002b; Turner, Iliffe, Downs, Bryans, Wilcock & Austin, 2003; Wilcock, Iliffe, Walters, Rait, Austin, Turner, Bryans, Downs, Levin, O'Carroll & Keady, 2002) and results (Bryans *et al* 2003; Downs *et al* 2003; Turner, Iliffe,

Downs, Wilcock, Bryans, Levin, Keady & O'Carroll, 2004; Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., O'Carroll, R., Howie, K., and Iliffe, S., 2006).

1.8 Purpose of current study

This study builds on the work of the recent previously discussed study by Downs *et al* (2003). As previously stated, this study sought to investigate the impact of training for practitioners on their detection and management of dementia, as well as carers' experiences of primary care for their relative with dementia, knowledge of services and satisfaction with primary care. In the course of this study, semi-structured interviews with carers yielded qualitative information on a number of topics. These included the first signs of dementia carers noted; what they thought of the response they received from primary care when they reported their concerns; what would improve life for their relative; and what advice they would give other carers. Qualitative data was also gathered from practitioners within the practitioner questionnaire on their perceptions of the first signs of dementia. This data was not analysed as part of the main study and will be utilised in the current study in an exploration of the first signs of dementia noted by carers and primary care practitioners.

1.8.1 Aims of current study

The aims of this research are:

1. To explore carers' and Primary Care practitioners' perceptions of the first signs of dementia.
2. To explore the impact of training on Primary Care practitioners' perceptions of the first signs of dementia.
3. To explore the impact of sociodemographic and occupational factors on carers' and primary care practitioners' perceptions of first signs of dementia.

1.8.2 Research questions

1. Is there concordance between carers and Primary Care practitioners about the first signs of dementia?
2. Do age, gender, knowledge of dementia, relationship to the person with dementia and living situation have an effect on carers' reported perceptions of the first signs of dementia?
3. Do age, gender, knowledge of dementia, occupational discipline and previous experience of dementia have an effect on practitioners' reported perceptions of the first signs of dementia?
4. Does training in the diagnosis and management of dementia for Primary Care practitioners have an effect on their perceptions of the first signs of dementia?

2 Method

2.1 Ethical Approval

Ethical permission was sought to carry out the parent study entitled "Improving the response of primary care practitioners to people with dementia and their families: A randomised controlled trial of educational interventions". Permission was obtained from Local Research Ethics Committees in Lothian, Forth Valley and Fife in Scotland, and Barnet and Camden & Islington in London. A new analysis of the data gathered in that study was planned in the current project. Guidance was sought from Lothian Research Ethics Committee as to the need to seek further ethical approval. This guidance indicated that further ethical approval was not required as the current study intended to analyse data previously collected, further recruitment was not intended and the author was one of the original research team (for response from Lothian Research Ethics Committee 3, see appendix 1). Permission was given by the grantholder of the main study, Professor Murna Downs, Head of the Bradford Dementia Group, for the data to be used in a new analysis (for letter of permission from Professor Downs see appendix 2).

2.2 Design

A between-participants design was adopted to investigate differences between carers and practitioners in reported first signs of dementia. A within-participants design was adopted to investigate the effect of training for practitioners on first signs of dementia reported. The effect of age, gender, relationship to person with dementia, knowledge of dementia, living situation and level of contact with their relative with dementia on

reported first signs of dementia were examined in relation to carers of people with dementia. The effect of practitioners' age, gender, knowledge of dementia, occupational discipline, post-graduate training and level of contact with people with dementia on perceived first signs of dementia were also examined.

2.3 Participants

The current study utilises data collected from carers and primary care practitioners who participated in the Downs *et al* (2003) study. Participants were recruited to this study as follows:

2.3.1 Primary care practices

The study took place in two sites in the UK. The first site was in Central Scotland and recruited participants to the study from Primary Care practices in Lothian and Forth Valley Health Boards. The study base for this site was at the University of Stirling. The second site was in London and included practices from within Barnet, and Camden & Islington Health Authorities. The study base for this site was at the Royal Free and University College Hospitals Medical School. All primary care practices within these sites that met inclusion criteria were approached.

Inclusion criteria for practices were:

The practice had to be computerised in order for researchers to access the medical records of people with dementia, and to allow the possible installation of decision-support software into the practice system.

- Practices had to use a Windows operating system to support software, and all staff within the practice had to have access to a PC.
- A meeting area was required within the practice in which small group practice based workshops could take place.

Exclusion Criteria for practices were:

- Practices without the above technical requirements were excluded
- Practices with no registered patients aged 75 or over were excluded. This criterion applied to only one practice, which was a University practice, where the practice list was comprised of a student population.

Approach to practices was through a variety of methods and utilised the main organisational structures within each area. Letters and information packs about the study were sent to all practices in each study site. This initial contact was then followed up by one or more members of the research team through a combination of telephone calls, meetings with practice managers and presentations to primary care practitioners. Presentations were made at the individual practice level, and at local and regional level through locality groups, Local Health Care Co-operatives, research

groups and discipline-specific meetings, such as nurse meetings. Thirty-five practices were recruited to the Downs *et al* (2003) study using this method, all of which were included for the purposes of the current study.

2.3.2 Primary care practitioners

All grades of medical, nursing and social work professionals working in the practice were invited to take part in the study. It was recognised, however, that the subject matter of the study would have varying degrees of relevancy to practitioners within each practice. Therefore, practices were requested to nominate eligible practitioners for inclusion based on the relevancy of the subject matter. Some practitioners who had no contact with older people through their work excluded themselves, for example Health Visitors dealing predominantly with pre-school children.

Three training interventions were developed by the research team and tested in the study: small group practice-based workshops; an electronic tutorial carried on a CD-ROM; and decision support software built into the electronic medical record used in general practice. Practices were randomly assigned to either one of the intervention arms, or to a control group, where only baseline and outcome measures were gathered and where normal care continued. The control group received no intervention throughout the course of the study.

Those practitioners who received either workshop-based training or computer-based training in the form of a CD-Rom were given continuing education credits following

completion of training. Practices in the Control group were offered training in the form of their choice following completion of the study. Education credits were not available for those practices in the Decision Support arm of the study due to the nature of the materials, which are accessed on an 'as-required' basis. A total of 204 primary care practitioners, which included 78 nurses and 126 general practitioners, were recruited to the study using this method.

2.3.3 Carers of people with dementia

Carers of people with dementia were identified for inclusion by the primary care practice through a process designed to maintain their right to confidentiality until they agreed to inclusion in the study. Initially, the practice staff were asked to identify patients on their practice list who had a formal diagnosis of dementia, or who had "probable dementia", in the opinion of the GP or specialist with diagnostic responsibility e.g. hospital physician, psychiatrist. Practice staff then identified whether those patients had contact with an individual who could be defined as an informal carer.

The working definition of an informal carer has been proposed by the Carers' (Recognition and Services) Act (Department of Health, 1995) as "an individual giving a substantial amount of unpaid care on at least a weekly basis". For the purpose of the study, a carer was defined as a family member or other unpaid individual who provided care on at least a weekly basis. Practices were then asked to record whether the carers named were aware of their relative's diagnosis of dementia according to the

GP, practice team member or other professional. Carers were not considered as eligible for inclusion in the study if the practice stated that they had not been made aware of their relatives' diagnosis, or if there was uncertainty as to whether this diagnosis had been passed to the carer, in order to avoid the situation whereby carers were in receipt of less information than the researcher.

One hundred and ninety-three carers were identified by practices as eligible for inclusion in the study pre-intervention. Of these, 129 agreed to be interviewed following contact from the practice. Two carers subsequently withdrew leaving a sample of 127 carers pre-intervention. An additional 59 carers were identified by practices post-intervention as being carers of people diagnosed with dementia since an intervention was introduced. Of this number, 40 agreed to inclusion in the study. This post-intervention sample have not been included in analysis for the purpose of the current study as Downs *et al* (2003) found no change on any carer measure following introduction of an intervention in their relatives' primary care practice. It is possible that measures were not sensitive enough to pick up change in the carer group, and that changes may have occurred in areas not analysed within the Downs *et al* (2003) study. For the purposes of the present study, analysis of post-intervention carer data is not required to answer the research questions and has therefore not been examined.

2.4 Procedure

The current study involves a new analysis of data from a randomised controlled trial of educational interventions carried out by Downs *et al* (2003). It is, therefore, important to outline the procedures utilised to generate data within that study.

2.4.1 Data collection

Following recruitment of primary care practices, recruitment of practitioners and carers of people with dementia was completed. The following procedure was adhered to within each group to generate data for analysis:

Primary care practitioners

As soon as practices identified practitioners eligible for inclusion, a member of the research team delivered a questionnaire to give to each practitioner to complete. This questionnaire was developed by the research team and piloted within one primary care practice in an area outside the main study to avoid contamination of the study population, before being utilised in the main study. This pilot practice was representative of the average primary care practice in terms of demographic and patient list profile. Following completion of questionnaires, a member of the research team visited the practice to collect them, maintaining face-to-face contact with the participants. This procedure was repeated post-intervention.

Carers

Once practices were recruited to the study, and had identified eligible carers for inclusion, initial contact was made with these carers by the practice to introduce the study. This initial contact, in the form of a letter or phone call from the practice, requested consent for a member of the study team to make contact directly with the carer. If consent was given, their details were then passed to the relevant member of the study team in that site. On contact with the carer, the researcher confirmed consent to take part in a structured interview and arranged a convenient time and place for interview. Written material about the purpose of the study and the interview process was then sent out to carers.

On completion of the interview, carers were asked for consent to contact them post-intervention for a follow-up interview i.e. once their relatives' primary care practice had received an educational intervention, or in the case of control practices, at least 9 months after the date of the last carer interview. Consent to access their relatives' medical records was also discussed at this interview. If the carer considered that their relative could give informed consent to access their records, they were asked to discuss this request with their relative and to ask them to sign written consent to access their records. If they considered their relative unable to give informed consent, the carer was asked to consider giving proxy consent to access their relatives' records, based on their knowledge of what their relative would agree to. All ethics committees to whom the study had applied passed this process.

At post-intervention stage (no less than 9 months from date of intervention), all carers interviewed pre-intervention were contacted for follow-up interview if they remained eligible. They became ineligible if the person with dementia had died or had left the practice.

2.4.2 The current study

The current study involved a novel analysis of data gathered in the Downs *et al* (2003) study. The sample used for analysis in this study consisted of all practitioners and all pre-intervention carers from Downs *et al* (2003). A new dataset has been extrapolated from that used for analysis previously. This dataset contains a novel set of variables relating to the first signs of dementia reported by carers and practitioners. The specific question series used will be outlined in the next section.

In order to answer the research questions of this study, the relationships between first signs noted and sociodemographic, relational and occupational factors had to be identified. As information on the first signs of dementia was recorded verbatim, a qualitative analysis of this data was required before this data could be utilised in statistical analysis. Qualitative analysis also facilitated an exploration of the language and concepts used by informal carers and practitioners in relation to dementia. Due to the nature of the data collected and the design of the study, a grounded theory approach was viewed as the most appropriate method of managing and analysing verbatim material. The procedural aspects of managing this material will be described in the following section.

2.4.3 Management of qualitative data using the grounded theory approach

A grounded theory has been defined as

> "one which is inductively derived from the study of the phenomenon it represents"
>
> (Strauss & Corbin, 1990)

The grounded theory approach was first developed by Glaser & Strauss (1967), who ascertained that this approach could be used by many disciplines, as each would bring their own perspective to the work, and the evolving theory would reflect this perspective. It is a "bottom-up" approach to understanding a phenomenon, in that a phenomenon of interest is studied and findings from that study allowed to emerge, rather than studying it with the intention of proving or disproving a previously held theory about it.

This approach to qualitative data involves the generation of theory about what may be going on within a phenomenon by the intensive and systematic analysis of material gathered from the participants interacting within that phenomenon (Strauss, 1987), and involves comparison and coding throughout analysis of the main concepts emerging from the data.

One of the core concepts within grounded theory analysis is that of theoretical sensitivity (Strauss & Corbin, 1990), which refers to the ability to understand the meanings within data, gain understanding from it and separate what is significant in

the study of a particular phenomenon by constantly relating it back to the phenomena being studied, or data being analysed. Strauss & Corbin (1990) state that theoretical sensitivity develops through the following actions:

1. Becoming familiar with the literature in the area of interest – this can sensitise the researcher to important events within the area of study and give context and background to the work to be undertaken.

2. Having professional experience in the field – having some background in the field of study can allow the researcher a greater, or more rapid, insight into a phenomenon. Strauss & Corbin (1990) give the example of carrying out a grounded theory study in a hospital environment where the researcher with some experience of hospital systems would perhaps gain insight more quickly to the important concepts for participants in this environment than someone with no previous exposure to this environment.

3. Having personal experience – this can help the researcher to make comparisons between their own and others' experience of a phenomenon. However, Strauss & Corbin (1990) also point out the importance of reflection on the behalf of the researcher, to ensure they are open to new concepts derived from their participants as well as having prior sensitivity through personal experience.

4. The analytic process – the process of carrying out analysis on qualitative data also encourages the development of theoretical sensitivity by immersing the researcher in information, ideas and concepts relevant to the field of study. Therefore, throughout the course of an analysis, the researcher develops greater insight and understanding through interaction with the data.

The author of the current study has studied previous work in the field and was fully involved in the collection of the data from participants within the study. The author also has extensive experience as a professional working with people with dementia and their families in clinical settings and in a research setting, and personal experience of being a family carer for someone with dementia. The author therefore had a degree of theoretical sensitivity, according to the definition of sensitivity given by Strauss & Corbin (1990), before undertaking a grounded theory analysis of the data available.

The first step in an analysis of qualitative data from this perspective involves an examination of previous literature in the field. Here, this work highlighted a number of important factors. As discussed in section 1.4, practitioners working within the area of dementia report difficulties in the early recognition of dementia. McIntosh Swanson, Power & Rae (1999) found that dementia care was a source of stress for GPs and nurses, and few GPs thought that their profession had a principal role to play in managing the condition. Trickey *et al* (2000) found similar findings in their study of nursing staff. Both studies concluded that this reticence might reflect a desire to be less involved in day-to-day management of a phenomenon that they find anxiety provoking. Resistance to engage in the process of managing the condition may lead to

less experience of that condition, and therefore increased difficulty in reporting signs that they think are indicative of dementia. Any analysis of data relating to practitioner reports of first signs of dementia must remain sensitive to the reported difficulties of participants in dealing with the condition since this may affect what they are able to report.

La Rue, Watson & Plotkin (1993) found that carers of people with dementia differ in their reporting of first signs of dementia and also have difficulty in reporting first signs under certain conditions. These conditions included their current sense of burden and stress, and their relationship to the person with dementia, with non-spouse carers reporting more symptoms than spouse carers. Within the current study, the characteristics of the sample formed an integral part of the analysis and the literature gave some insight into the factors that may be important.

The current study aimed to utilise the techniques used in a grounded theory analysis to develop an explanatory framework for understanding the perceptions of carers and practitioners relating to the first signs of dementia and to gain insight into the perspectives of these individuals.

Context was considered to be the first important factor in analysis. Grounded theory develops from within a particular context, and aims to meet the scientific principles of generalisability and reproducibility, although these terms must be redefined to fit within a qualitative framework. Strauss & Corbin (1990) highlight the fact that any

study of social phenomena is only reproducible within the same population and context within which it was developed, and can only be generalised within that population. They also suggest that, as in quantitative research, more systematic and widespread sampling procedures will result in greater generalisability, as well as precision and predictive capacity. Within the current study, sampling involved the inclusion of all carers and practitioners from Downs *et al* (2003), in which strict inclusion and exclusion criteria were set to enhance reproducibility. The carer sample within this study is comparable to samples from previous work (Alzheimer's Disease Society, 1995, 2000; LaRue & Plotkin, 1999), as is the practitioner sample (Trickey *et al*, 2000; Swanson *et al*, 1999). Carers and practitioners were aware that the study was set within the context of an examination of the process of identifying and managing dementia.

The current study aimed to develop theoretical concepts that would illuminate the phenomena of first reported signs of dementia by two groups known to be closely involved with individuals within the earlier stages of the condition, carers and primary care practitioners. Participants were asked to respond to questions that were situated within the context of early signs of dementia.

Practitioners were asked to respond to the statement question:

> "Please state, in order of importance, the signs that you consider are indicative of the first stages of dementia ".

This question came within a series of questions relating to the diagnosis and early identification of dementia, contextualising it for respondents. There were no pre-coded or scaled response choices available for this question, and practitioners were free to record whatever signs they thought were indicative of the first stages of dementia.

Carers, in a face-to-face interview, were asked to respond to a series of questions about the time when it was first noticed that something was wrong with their relative. Within this series of questions, there was a question specifically on what was noticed that made them think something was wrong.

The question series used was:

a) Can you tell me how long ago it was first noticed that something was wrong?

b) Who noticed it?

c) What was it that was noticed?

d) What did you think was causing it?

Responses to question "c) What was it that was noticed?" were analysed as first signs of dementia, since responses to this question concentrated on the signs and symptoms first displayed by relatives with dementia. This short series of questions was further situated within a set of questions relating to the process of diagnosis of dementia for their relative, in order to contextualise the process for respondents.

The wording of the questions relating to first signs for carers and practitioners were necessarily different, to reflect the different language style and background of each

group, since increasing understanding of what is being asked is as important as maintaining generalisability. However, responses remain valid for qualitative analysis since efforts were made to contextualise the phenomenon in the same way for both groups of participants.

Responses to the aforementioned questions were analysed following the principles of grounded theory. The NVIVO 2.0 computer package was used as a 'tool' to assist in the analytic searching, management and organisation of the data.

According to the principles of data analysis using a grounded theory approach, data analysis was undertaken in two stages (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990). Data was initially analysed using a method of 'open' coding, in which each response from each participant was analysed individually. This type of 'line-by-line' coding, whilst labour-intensive, has an important function in that it submerges the researcher completely in the raw data and facilitates the emergence of themes and categories from the data. All participant responses were coded in this manner until the data had been exhausted.

A second level of coding, 'selective' coding, was then employed to link common themes identified during the process of 'open' coding. This process involved re-analysing transcripts of responses and linking common themes identified at the first stage of coding. This level of coding is necessarily more interpretative than 'open'

coding, however it remains grounded in the data since it uses emergent themes from the first level of coding.

The themes emerging from selective coding were re-examined and a further level of interpretative analysis undertaken to define categories of first signs of dementia reported by carers and practitioners. Previous research in the area was used as a tool to guide this final level of analysis. The categorisation of signs of dementia included in "Dementia in the community: Management strategies for general practice" (Alzheimer's Society, 1995b) was produced following research into primary health care provision for people with dementia and their families, and is therefore relevant to the context of the current study (see appendix 5). This overall classification system was used to group themes emerging from the previous level of analysis into areas of commonality, which were classified as subcategories. These subcategories were grouped under five main categories relating to a domain of functioning in which change may be noted in dementia; cognitive; behavioural; emotional; physical; and other. Again, the definition of these main categories was guided by the use of the Alzheimer's Society classification system. To promote transparency of analysis and enhance reproducibility of the study, a full categorisation of all responses was produced (see appendix 6).

2.5 Measures

Practitioner questionnaires utilised by Downs *et al* (2003) generated measures of: sociodemographics; knowledge of services; knowledge of dementia; confidence in identification and management of dementia; attitudes towards dementia; and factors impeding care of people with dementia.

From the available practitioner measures, the following were utilised within the current study:

1. Sociodemographic measures

- Age (years)
- Gender (male/female)
- Grade of practitioner
- Employment status (full- or part-time)
- Discipline (doctor or nurse)
- Length of time since qualification (years)
- Relevant post-graduate training (old age psychiatry, general psychiatry or geriatric medicine)
- Contact with people with dementia (caseload, monthly contact rates)

2. Knowledge of dementia

The use of a dementia care knowledge quiz to assess practitioner knowledge of the subject, and to evaluate the efficacy of teaching programmes, is well established in the literature (Barrett, Haley, Harrett & Powers, 1997; Edwards, Plant, Novak, Beall & Baumhover, 1992). A 14-item multiple choice quiz was developed for use in this study which drew on components of the Alzheimer's Disease Knowledge Test for Health Professionals devised by Barrett *et al* (1997) and the Alzheimer's Disease Knowledge Test devised by Deickmann, Zarit, Zarit & Gatz (1988). Both these measures have been widely validated with health care professionals. The purpose of the practitioner quiz was to assess clinical knowledge in the areas of current and future prevalence, risk factors, diagnosis (including differential diagnosis), medication and management. Items on the quiz were multiple choice, with four possible answers and a 'don't know' response available for each item. The quiz was piloted with one practice outwith the study population. Cronbach's alpha correlation coefficient, a measure of the internal consistency of items within a scale, was 0.70 for the practitioner quiz. 0.70 represents a high measure of consistency between items on a scale, where alpha is 0.0 – 1.0. (See appendix 3 for a copy of the practitioner quiz).

Practitioners were also asked to rate their own current knowledge of dementia on a scale of 1-10, and rate priority to update their knowledge on a scale of low; moderate; high. Practitioner questionnaires were completed pre- and post- intervention. The same questionnaire was completed post-intervention, with the addition of a section on evaluation of the intervention in those practices that had been given an educational package.

Carer questionnaires generated measures of: sociodemographics; knowledge and use of services; knowledge of dementia; unmet need; and satisfaction with primary care support.

From the available carer measures, the following were utilised within the current study:

1. Sociodemographic profile

- Age (years)
- Gender (male/female)
- Relationship to person with dementia
- Living situation of carer in relation to person with dementia (lives with relative/ does not live with relative)
- Marital status (spouse/non-spouse)
- Number of dependents (children <18 years still living at home)
- Other caring commitments.

2. Carer knowledge of dementia

This was measured through responses to a quiz comprising 20 true/false statements. The quiz included items from a scale developed by Maas & Buckwalter (1990) and a survey study by Cutler (1987), both of which have been validated with large numbers of carers. Additional questions were developed by Downs *et al* (2003) to reflect the content of the educational interventions, in order to measure whether any change in

practitioner knowledge or practice post-intervention was reflected in a change in carer knowledge. The quiz was piloted as an independent measure, and as part of the carer interview schedule, with carers of people with dementia in Glasgow, outwith the study sites in Forth Valley and London. Cronbach's alpha statistic for the scale was 0.76. This demonstrates a high degree of internal consistency (See appendix 4 for the carer knowledge quiz).

2.6 Analyses

In the current study the data was analysed in three stages:

1. Exploration and description of the sample.
2. Content analysis of verbatim information gathered about the first signs of dementia noted by carers and practitioners.
3. Statistical analysis.

2.6.1 Exploration and description of the sample

In order to contextualise the data, an exploration and description of the characteristics of this sample was carried out. This also facilitated comparison of the sample with participants in previous research in this area.

2.6.2 Content analysis

This analysis of verbatim responses to questions about the first signs of dementia was carried out using a grounded theory approach, as outlined within Section 2.4.3 on procedure. The purpose of this analysis was the development of dichotomous variables from verbatim responses, which were then utilised in statistical analysis. The emerging categories and subcategories of first signs of dementia noted from this analysis are given within the Results section.

2.6.3 Statistical analysis

Content analysis of verbatim responses resulted in the production of categories of first signs of dementia as outlined above, and each participant was recorded as either reporting a sign within each category or not. This was also applied to subcategories within each main category to allow a more detailed exploration of the data.

Independent sample t-tests were carried out to identify whether carer age, level of contact with their relative and knowledge about dementia were related to each of the categories of first signs reported by carers. Independent sample t-tests were also carried out on practitioner data to identify whether practitioner age, number of contacts with patients with dementia and knowledge of dementia were related to first signs reported by practitioners. For the purpose of analysis, relationship to person with dementia was transformed into the dichotomous variable spouse/non-spouse, and living situation was transformed into resident/not resident with the person with dementia. A 2x2 chi-square analysis was carried out to explore whether there was a

relationship between the variables gender, relationship to person with dementia and living situation, and each of the categories of first signs of dementia. The same analysis was carried out on each of the practitioner variables gender, occupational discipline (nurse or doctor) and relevant post-graduate training (yes or no) to identify significant relationships between these variables and each category of first signs of dementia.

A 2x2 Chi-square analysis of the proportion of carers and practitioners within each category and subcategory of first signs of dementia was carried out to identify whether there were significantly different proportions of participant type within each. 2x2 chi-square tests were also carried out to identify whether there was a difference in the reporting of first signs of dementia reported by practitioners before and after training.

Significance levels were set at $p < .05$ with a view to the exploratory nature of the study.

All analyses for this study were carried out using the Statistical Package for Social Sciences for Windows, Version 11.0.

3 Results

3.1 Exploratory Data Analysis

This yielded information about the sociodemographic profile and knowledge base of participants.

3.1.1 Exploration of carer sample

Gender

One hundred and twenty-two carers were included in the analysis, 36 of whom were male (29.5 per cent), and 86 of whom were female (70.5 per cent).

Age

As can be seen in Table 3.1, there was very little difference between the mean age of male and female participants. The mean age of the whole sample was 62.90 years (range 27.61 - 93.14, S.D. 13.05).

Table 3.1: Carer age by gender

Carer Gender	N	Minimum Age	Maximum Age	Mean age in years	Std. Deviation
Male	36	38.01	93.14	62.50	14.35
Female	86	27.61	87.55	63.08	12.55
Total	122	27.61	93.14	62.90	13.05

The majority of carers were in the 45-54 and 55-64 year-old age bands. However, almost a quarter of the carer sample (23.8 per cent) were themselves 75 years old or

above. A breakdown of the number of carers in each 10-year age band between 25 and 94.99 years old is presented in Table 3.2.

Table 3.2: Carers within each 10-year age band from 25-94.99 years old

Carers age (Banded)	Number of carers	Per cent
25.00 - 34.99 years old	1	0.8
35.00 - 44.99 years old	7	5.7
45.00 - 54.99 years old	28	23.0
55.00 - 64.99 years old	37	30.3
65.00 - 74.99 years old	20	16.4
75.00 - 84.99 years old	24	19.7
85.00 - 94.99 years old	5	4.1
Total	122	100.0

Level of contact

Fifty-eight carers (48 per cent) did not live with their relative with dementia. Within this non-cohabiting group, the mean number of face-to-face visits to their relative in a week was 6.8 (range 0.17 – 42.0 visits per week, S.D. 7.6) and the mean time spent with their relative on each visit was 170.9 minutes (range 15.0 – 2880.0 minutes, S.D. 376.2). The mean number of hours in a week spent by these carers in direct contact with their relative with dementia was 10.6 hours (range 0.25 - 56.00 hours, S.D. 10.7).

Level of knowledge

One hundred and one carers (82.8 per cent) completed the dementia knowledge quiz (Downs *et al.* 2003). Twenty -one carers declined to complete the quiz. The mean

score out of 20 and quiz score expressed as a percentage for the total sample, and by gender, marital status and co-habitation status is shown in Table 3.3.

Table 3.3: Carer quiz scores by gender, marital status and co-habitation status

		Total carer quiz score/20			
	N	Mean	S.D.	t	p
Gender: Male	30	12.00	3.00	0.24	0.815
Female	71	12.00	4.00		
Co-habiting: Yes	51	11.00	4.00	1.26	0.210
No	50	12.00	3.00		
Spouse Yes	32	11.00	3.00	2.07	0.52
No	69	12.00	4.00		
Total sample	101	11.84	3.47		

Relationship to the person with dementia

The carers' relationship to the person with dementia is shown in table 3.4. below.

Table 3.4: Relationship of carer to person with dementia

Relation of carer to patient	Number of carers	Per cent
Wife	24	19.7
Husband	17	13.9
Partner	1	0.8
Daughter	40	32.8
Daughter in law / stepdaughter	10	8.2
Son	23	18.9
Other relative (cousin, niece, nephew)	6	4.9
Other (informal unpaid, friend)	1	0.8
Total	122	100.0

Forty-two carers (34.4 per cent) were the spouse of the person with dementia and 80 (65.6 per cent) were non-spouses.

Living situation

Sixty-four carers (52.5per cent) lived with their relative with dementia and 58 (47.5 per cent) did not. A breakdown of the relationship between co-habiting carers (those who lived with their relative) and the person with dementia is shown in table 3.5.

Table 3.5: Relationship between co-habiting carer and person with dementia

	Does carer live with relative?			
	Yes		**No**	
Relation of carer to person with dementia	Number	Per cent	Number	Per cent
Wife	24	37.5	0	0
Husband	17	26.6	0	0
Daughter	7	10.9	33	56.9
Daughter in law/ stepdaughter	5	7.8	5	8.6
Son	9	14.1	14	24.1
Other relative	1	1.6	5	8.6
Other	0	0	1	1.7
Partner	1	1.6	0	0

Number of dependent children

One hundred and fifteen carers (94.3 per cent) had no dependent children under the age of 18 living in the house. Three carers (2.5 per cent) had 1 child still living at home. The remaining 4 carers (3.3 per cent) had 2 children under 18 still at home.

Other caring commitments

Carers were asked about their other caring commitments. Sixteen carers (13.1 per cent) of the total sample described themselves as the main carer for someone else other than their relative with dementia or their children.

3.1.2 Exploration of practitioner sample

Gender

Two hundred and four health care practitioners were included in the analysis. One hundred and twenty-six of these were GPs and the remaining 78 were nurses. The majority of participants were female (N = 138, 68 per cent of sample). A breakdown of the gender distribution of participants can be seen in Table 3.6.

Table 3.6: Gender of practitioner by discipline (GP or nurse)

Practitioner sample	Gender		Total
Discipline: GP or nurse	Male	Female	
GP	65	61	126
Nurse	1	77	78
Total	66	138	204

Age

One hundred and seventy-eight practitioners chose to give their date of birth. The mean age of this sample was 44.35 years (range 28.49 – 68.73, S.D. 8.07). There was a significant difference between the mean age of GPs and nurses, but no significant difference between the mean age of male and female practitioners, as can be seen in Tables 3.7 and 3.8.

Table 3.7: Practitioners age by discipline

Practitioner discipline	N	Age range	Mean age in years	Std. Deviation	t	p
GP	112	28.49 - 68.73	42.81	8.07	3.12	**0.002***
Nurse	66	30.39 - 62.49	46.94	9.25		
Total	178	28.49 - 68.73	44.35	8.74		

***p < .05**

Table 3.8: Practitioners age by gender

Gender of practitioner	N	Age range	Mean age in years	Std. Deviation	t	p
Male	55	30.67 – 68.73	44.09	8.55	0.26	0.793
Female	123	28.49 – 62.49	44.46	8.85		
Total	178	28.49 – 68.73	44.35	8.74		

Level of contact

A small proportion of practitioners, 36 (17.7 per cent), could estimate how many patients with dementia were on their caseload at present. The mean number of people with dementia per caseload within this group was 14.10 (range 1.00 – 100.00, S.D. 23.56). One hundred and thirty-seven (67 per cent) practitioners could estimate the

number of consultations with people with dementia they had in a month. The mean number of consultations with people with dementia was 8.22 (range 0.00 – 100.00, S.D. 12.33), equivalent to a mean weekly contact rate for practitioners of 2.06 (range 0.00 – 25.00, S.D. 3.08).

Level of knowledge

Two hundred and one practitioners (98.5 per cent of the total sample) completed the dementia knowledge quiz developed by Downs *et al* (2003) at the pre-intervention stage. Three practitioners did not attempt the quiz for unknown reasons. The quiz score (expressed as the number of correct responses out of a possible 14) for the total sample, and by discipline and gender, is shown in Table 3.9.

Table 3.9: Practitioner quiz scores by gender and discipline

		Quiz score/14			
	N	Mean score/14	Std. Deviation	t	p
Gender Male	66	9.32	2.11	3.24	**0.001***
Female	135	8.10	2.69		
Discipline GP	126	9.25	2.24	5.83	**0.001***
Nurse	75	7.23	2.61		
Total	201	8.5	2.57		

***p < .05**

Results indicate a significant effect of gender on quiz score. Males had a higher mean quiz score (N = 66, mean = 9.32, SD = 2.11) than females (N = 135, mean = 8.10, SD = 2.69), which is a medium effect size (d = 0.51). There was also a significant effect of occupational discipline on quiz scores, with GPs having a significantly higher quiz

score (N = 126, mean = 9.25, S.D. = 2.24) than nurses (N = 75, mean = 7.23, S.D. = 2.61), which is a large effect size (d = 0.84).

Relevant training

Downs *et al* (2003) defined previous training relevant to the diagnosis and management of dementia within the following areas, prior to inclusion in the study:

- Elderly medicine
- General psychiatry
- Old age psychiatry
- Community psychiatric nursing
- Dementia studies
- Mental health nursing

Seventy-eight (38.2 per cent) practitioners had previously undertaken training in one of the areas above, the remaining 126 (61.8 per cent) had not. Table 3.10 shows the number of practitioners who had undertaken training by discipline, and the effect of previous training on quiz scores.

Table 3.10: Practitioners who had undertaken training by discipline and effect on quiz score

Practitioner discipline	Relevant training	N	Mean quiz score/14	Std. deviation	t	p
GP	No	54	9.39	2.07	0.58	0.561
	Yes	72	9.15	2.37		
	Total	126	9.25	2.24		
Nurse	No	69	7.09	2.60	1.59	0.116
	Yes	6	8.83	2.32		
	Total	78	7.23	2.61		

Results indicate no significant effect of previous training on quiz scores for either GPs or nurses.

3.2 Content analysis

Categories and subcategories of the first signs of dementia were defined using the process outlined in Method section 2.4.3 (pp.52-56). This process generated five main categories; Cognitive signs; Emotional signs; Behavioural signs; Physical signs and Other signs. Within these five main categories, 32 subcategories were identified. Signs named within subcategories, as stated previously in Section 2.4.3, shared a commonality. Subcategories were grouped under a main category, and shared a common theme. A list of all categories and a flowchart highlighting the relationship between categories and subcategories is given in Appendix 6.

Table 3.11 below highlights the number of carers and practitioners from the total sample of each group who named a sign from within each of the 5 main categories and 32 subcategories at the pre-training intervention stage (Time 1).

Table 3.11: First signs of dementia reported by carers and practitioners at pre-intervention stage

Categories/subcategories of dementia	Carers (N = 122) N (% of total sample)	Practitioners (N = 204) N (% of total sample)
Cognitive signs	90 (73.8)	188 (92.2)
Memory impairment non-specific	22 (18.0)	73 (35.8)
Short-term memory impairment	14 (11.5)	70 (34.3)
Being forgetful	43 (35.2)	46 (22.5)
Cognitive change	1 (0.8)	18 (8.8)
Executive function problems	1 (0.8)	20 (9.8)
Language disorder	8 (6.6)	16 (7.8)
Psychiatric phenomena	6 (4.9)	12 (5.9)
Perseveration and repetition	21 (17.2)	15 (7.4)
Being confused	16 (13.1)	57 (27.0)
Emotional signs	13 (10.7)	78 (38.2)
Emotional change non-specific	4 (3.3)	5 (7.5)
Personality/temperament change	3 (2.5)	45 (22.1)
Depressed mood	1 (0.8)	30 (14.7)
Anxiety	2 (1.6)	10 (4.9)
Irritability/hostility	4 (3.3)	4 (2.0)
Lack of emotional response/lability	4 (3.3)	3 (1.5)
Behavioural signs	52 (42.6)	154 (75.5)
Behavioural change non-specific	6 (4.9)	45 (22.1)
Withdrawal/apathy	5 (4.1)	5 (2.5)
Agitation and restlessness	6 (4.9)	32 (15.7)
Aggressive behaviour	2 (1.6)	7 (3.4)
Difficulty with purposeful tasks	13 (10.7)	20 (9.8)
Disorientation/getting lost	9 (7.4)	43 (21.1)
Losing/hoarding/hiding things	18 (14.8)	5 (2.5)
Self care abilities	6 (4.9)	58 (28.4)
Social behaviour	5 (4.1)	12 (5.9)

Table 3.11 (Cont) **Categories/subcategories of dementia**	**Carers (N = 122) N (% of total sample)**	**Practitioners (N = 204) N (% of total sample)**
Physical signs	23 (18.9)	26 (12.7)
Physical change non-specific	9 (7.4)	3 (1.5)
Nutritional concerns	3 (2.5)	7 (3.4)
Mobility disturbance	1 (0.8)	6 (2.9)
Sleep disturbance	3 (2.5)	5 (2.5)
Level of continence	1 (0.8)	6 (2.9)
Falls and accidents	8 (6.6)	5 (2.8)
Other signs	15 (12.3)	23 (11.3)
Informant report	6 (4.9)	15 (7.4)
Non-categorised	9 (7.4)	11 (5.4)

Participants were coded as having either named (Yes) or not named (No) a sign from within each category and subcategory. This dichotomy (Yes or No) was then used in statistical analysis to compare those who had responded "Yes" to those who had responded "No" to the reporting of each subcategory and category of first sign of dementia.

3.3 Statistical Analysis

3.3.1 Carer sample

Independent sample t-tests were carried out to identify whether carer age, level of contact with their relative and knowledge about dementia were related to each of the categories and subcategories of first signs of dementia reported by carers. Where less than two carers reported a sign within a category or subcategory, no analysis was possible, indicated in the following tables by 'no analysis possible'.

Cognitive signs

Tables 3.12, 3.13 and 3.14 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Cognitive Signs" is explored.

Table 3.12: Effect of carer age on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Cognitive signs reported	Yes	90	62.52	13.27	0.55	0.586
	No	32	63.99	12.55		
Memory impaired (nos)	Yes	22	65.12	11.23	0.88	0.382
	No	100	62.42	13.42		
Short term memory impaired	Yes	14	58.36	11.73	1.39	0.167
	No	108	63.55	13.15		
Being forgetful	Yes	43	61.59	14.05	0.82	0.413
	No	79	63.62	12.51		
Cognitive change	Yes	1	No analysis possible			
	No	121				
Executive function problems	Yes	1	No analysis possible			
	No	121				
Language disorder	Yes	8	60.84	14.96	0.82	0.646
	No	114	63.05	12.97		
Psychiatric phenomena	Yes	6	67.75	11.73	0.93	0.353
	No	116	62.65	13.11		
Perseveration and repetition	Yes	21	61.35	15.19	0.60	0.55
	No	101	63.23	12.63		
Being confused	Yes	16	62.94	14.73	0.01	0.99
	No	106	62.90	12.86		

Table 3.13: Effect of carer knowledge of dementia on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 101	Mean quiz score (%)	SD	t	p
Cognitive signs reported	Yes No	75 26	60.80 54.62	18.10 14.21	1.60	0.117
Memory impaired (nos)	Yes No	19 82	59.74 59.09	17.75 17.34	0.15	0.117
Short term memory impaired	Yes No	14 87	63.57 58.51	16.92 17.39	1.02	0.312
Being forgetful	Yes No	36 65	57.08 60.38	19.69 15.92	0.92	0.362
Cognitive change	Yes No	1 100	No analysis possible			
Executive function problems	Yes No	0 101	No analysis possible			
Language disorder	Yes No	5 96	69.00 58.70	10.84 17.49	1.30	0.197
Psychiatric phenomena	Yes No	4 97	67.50 58.86	15.55 17.39	0.98	0.331
Perseveration and repetition	Yes No	20 81	59.25 59.20	15.67 17.81	0.01	0.990
Being confused	Yes No	13 88	68.85 57.78	17.46 16.95	2.19	**0.031***

***p < .05**

Table 3.14: Effect of carer contact with relative (non-cohabitees) on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Cognitive signs reported	Yes No	45 13	11.77 6.43	11.26 7.67	1.60	0.115
Memory impaired (nos)	Yes No	10 48	14.04 9.86	11.41 10.57	1.13	0.266
Short term memory impaired	Yes No	8 50	8.44 10.92	9.54 10.96	0.24	0.813
Being forgetful	Yes No	22 36	10.47 10.64	8.53 12.00	0.06	0.952
Cognitive change	Yes No	0 58	No analysis possible			
Executive function problems	Yes No	1 57	No analysis possible			
Language disorder	Yes No	5 53	12.90 10.36	11.04 10.79	0.50	0.617
Psychiatric phenomena	Yes No	2 56	13.50 10.47	10.61 10.82	0.39	0.699
Perseveration and repetition	Yes No	14 44	6.38 11.91	5.88 11.61	1.71	0.094
Being confused	Yes No	6 52	11.99 10.41	5.87 11.19	0.37	0.738

Results indicate no significant effect of age or contact with their relative on the reporting of "Cognitive signs" of dementia. Knowledge of dementia had a significant effect on reporting signs within the subcategory "Being confused". Carers who reported a sign within this category had a higher mean quiz score (N = 13, mean = 68.85, SD = 17.46) than those who did not (N = 88, mean = 57.78, SD = 16.95). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 11.06, which is a medium effect size (d = 0.64).

Emotional signs

Tables 3.15, 3.16 and 3.17 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Emotional Signs" is explored.

Table 3.15: Effect of carer age on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Emotional signs reported	Yes No	13 103	62.65 67.94	10.28 13.33	0.07	0.941
Emotional change (nos)	Yes No	4 118	65.87 62.80	14.45 13.06	0.46	0.646
Personality/ temperament change	Yes No	3 119	61.31 62.95	13.12 13.10	0.21	0.832
Depressed mood	Yes No	1 121	No analysis possible			
Anxiety	Yes No	2 120	56.98 63.00	2.05 13.14	0.65	0.520
Irritability/ hostility	Yes No	4 118	66.30 62.79	10.15 13.15	0.53	0.598
Lack of emotion/ lability	Yes No	4 118	58.40 63.10	9.46 13.16	0.70	0.485

Table 3.16: Effect of carer knowledge of dementia on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 101)	Mean quiz score (%)	SD	t	p
Emotional signs reported	Yes No	11 90	51.81 60.11	18.07 17.12	1.51	0.135
Emotional change (nos)	Yes No	4 97	55.01 59.38	23.80 17.16	0.49	0.623
Personality/ temperament change	Yes No	2 99	45.00 59.49	35.36 17.02	1.17	0.244
Depressed mood	Yes No	0 101	No analysis possible			
Anxiety	Yes No	2 99	57.5 59.24	31.82 17.21	0.14	0.889
Irritability/ hostility	Yes No	4 97	53.75 59.43	12.50 17.51	0.64	0.523
Lack of emotion/ lability	Yes No	3 98	50.00 59.51	13.23 17.42	0.93	0.353

Table 3.17: Effect of carer contact with relative with dementia age on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Emotional signs reported	Yes No	7 51	11.89 10.39	19.86 9.16	0.34	0.732
Emotional change (nos)	Yes No	2 56	3.00 10.85	2.82 10.82	1.02	0.314
Personality/ temperament change	Yes No	2 56	30.50 9.86	36.06 8.99	2.83	**0.006***
Depressed mood	Yes No	0 58	No analysis possible			
Anxiety	Yes No	0 58	No analysis possible			
Irritability/ hostility	Yes No	3 55	8.17 10.71	2.84 11.00	0.39	0.694
Lack of emotion/ lability	Yes No	2 56	0.63 10.93	0.53 10.75	1.34	0.185

Age and knowledge of dementia had no significant effect on the reporting of "Emotional signs" of dementia. Contact with their relative with dementia had a statistically significant effect on reporting signs within the subcategory "Personality/temperament change". Carers in this category had a higher mean contact time per week in hours with their relative (N = 2, mean = 30.5, SD = 36.06) than those who did not (N = 56, mean = 9.86, SD = 8.99). The mean difference between the

'Yes' and 'No' conditions for this subcategory was 20.64, which is a large effect size (d = 0.91). However, due to the very small number of carers in the 'Yes' condition, this result must be viewed very cautiously and can only be viewed as a possible marker for future research in the area.

Behavioural signs

Tables 3.18, 3.19 and 3.20 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Behavioural Signs" is explored.

Table 3.18: Effect of carer age on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Behavioural signs reported	Yes	52	633.27	13.76	0.27	0.791
	No	70	62.63	12.60		
Behaviour change (nos)	Yes	6	61.97	13.43	0.18	0.858
	No	116	62.95	13.09		
Withdrawal/ apathy	Yes	5	69.59	17.54	1.17	0.244
	No	117	62.62	12.85		
Agitation and Restlessness	Yes	6	64.49	15.47	0.30	0.762
	No	116	62.82	12.99		
Aggressive behaviour	Yes	2	78.85	1.71	1.76	0.082
	No	120	62.64	12.99		
Difficulty with purposeful tasks	Yes	13	62.96	12.78	0.02	0.986
	No	109	62.90	13.14		
Disorientation/ getting lost	Yes	9	71.20	14.32	**2.01**	**0.047***
	No	113	62.24	12.78		
Losing/ hoarding/ hiding things	Yes	18	58.30	13.24	1.63	0.105
	No	104	63.70	12.92		
Self care abilities	Yes	6	53.32	9.23	1.86	0.065
	No	116	63.40	13.06		
Social behaviour	Yes	5	57.75	11.60	0.98	0.329
	No	115	63.47	12.79		

***p < .05**

Table 3.19: Effect of carer knowledge of dementia on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 101)	Mean quiz score (%)	SD	t	p
Behavioural signs reported	Yes No	42 59	58.93 59.41	17.65 17.25	0.14	0.812
Behaviour change (nos)	Yes No	5 96	52.00 59.58	17.18 17.35	0.95	0.343
Withdrawal/ apathy	Yes No	2 99	37.5 59.65	17.50 1.71	1.81	0.073
Agitation and Restlessness	Yes No	4 97	58.75 59.23	19.31 17.36	0.54	0.957
Aggressive behaviour	Yes No	2 99	62.50 59.14	10.61 17.47	0.27	0.788
Difficulty with purposeful tasks	Yes No	12 89	60.42 59.05	22.31 16.70	0.26	0.798
Disorientation/ getting lost	Yes No	6 95	55.00 59.47	21.45 17.14	0.61	0.542
Losing/ hoarding/ hiding things	Yes No	16 85	56.56 59.71	18.23 17.22	0.66	0.508
Self care abilities	Yes No	6 95	73.33 58.32	2.58 17.48	**2.09**	**0.039***
Social behaviour	Yes No	4 95	58.75 58.68	11.09 17.34	0.01	0.994

***p < 0.05**

Table 3.20: Effect of carer contact with relative with dementia age on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Behavioural signs reported	Yes No	23 35	12.74 9.15	10.96 10.50	1.25	0.216
Behaviour change (nos)	Yes No	3 55	6.00 10.83	4.50 10.94	0.76	0.453
Withdrawal/ apathy	Yes No	0 58	No analysis possible			
Agitation and Restlessness	Yes No	1 57	No analysis possible			
Aggressive behaviour	Yes No	0 58	No analysis possible			
Difficulty with purposeful tasks	Yes No	4 54	9.94 10.62	13.46 10.66	0.12	0.903
Disorientation/ getting lost	Yes No	3 55	4.00 10.93	3.00 10.90	1.09	0.280
Losing/ hoarding/ hiding things	Yes No	10 48	16.83 9.27	11.31 10.26	**2.08**	**0.042***
Self care abilities	Yes No	4 54	13.88 10.33	11.97 10.72	0.63	0.529
Social behaviour	Yes No	3 54	5.58 10.68	5.59 10.94	0.80	0.430

***p < .05**

Results of analyses show that carer age had a statistically significant effect on reporting signs within the subcategory "Disorientation/getting lost". Carers who reported a sign within this category had a higher mean age (N=9, mean = 71.2, SD = 14.32) than those who did not (N=113, mean = 62.24, SD = 12.79). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 8.96, which is a medium effect size (d = 0.66). Carer age did not have a significant effect on reporting of the main category of "Behavioural signs" or the reporting of subcategories other than "Disorientation/getting lost".

Carer knowledge of dementia had a statistically significant effect on reporting signs within the subcategory "Self care abilities". Carers who reported a sign within this category had a higher mean quiz score (N = 6, mean = 73.33, SD = 2.58) than those who did not (N = 95, mean = 58.32, SD = 17.48). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 15.02, which is a large effect size (d = 1.50).

Carer contact with their relative with dementia had a statistically significant effect on reporting signs within the subcategory "Losing/hoarding/hiding things". Carers reporting a sign within this subcategory had a higher mean contact time per week in hours with their relative (N = 10, mean = 16.83, SD = 11.31) than those who did not (N=48, mean = 9.27, SD = 10.26). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 7.55, which is a medium to large effect size (d = 0.70).

Physical signs

Tables 3.21, 3.22 and 3.23 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Physical Signs" is explored.

Table 3.21: Effect of carer age on reporting of "Physical signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Physical signs reported	Yes No	23 99	65.50 62.30	12.58 13.15	1.06	0.292
Physical change (nos)	Yes No	9 113	74.20 62.01	7.73 12.99	**2.77**	**0.007***
Nutritional concerns	Yes No	3 119	49.91 63.23	4.55 13.04	1.76	0.080
Mobility disturbances	Yes No	1 121	No analysis possible			
Sleep disturbance	Yes No	3 119	57.52 63.04	11.99 13.10	0.723	0.471
Level of continence	Yes No	1 121	No analysis possible			
Falls	Yes No	8 114	66.51 62.65	12.48 13.11	0.81	0.421

***p < .05**

Table 3.22: Effect of carer knowledge of dementia on reporting of "Physical signs" of dementia

	Sign reported	N (total = 101)	Mean quiz score (%)	SD	t	p
Physical signs reported	Yes No	19 82	62.37 58.48	15.67 17.70	0.14	0.812
Physical change (nos)	Yes No	8 93	55.00 59.57	15.58 17.50	0.95	0.343
Nutritional concerns	Yes No	3 98	63.33 59.10	10.41 17.52	1.81	0.073
Mobility disturbances	Yes No	1 100	No analysis possible			
Sleep disturbance	Yes No	2 99	62.50 59.14	24.75 17.32	0.27	0.788
Level of continence	Yes No	1 100	No analysis possible			
Falls	Yes No	6 95	67.50 58.68	14.41 17.43	1.2	0.229

Table 3.23: Effect of carer contact with relative with dementia age on reporting of "Physical signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Physical signs reported	Yes No	7 51	7.37 11.02	7.14 11.12	0.84	0.404
Physical change (nos)	Yes No	1 57	No analysis possible			
Nutritional concerns	Yes No	1 57	No analysis possible			
Mobility disturbances	Yes No	0 58	No analysis possible			
Sleep disturbance	Yes No	1 57	No analysis possible			
Level of continence	Yes No	0 58	No analysis possible			
Falls	Yes No	4 54	4.58 11.02	4.00 10.92	1.16	0.251

Carer age had a statistically significant effect on reporting signs within the subcategory "Physical change non-specific". Carers who reported a sign within this category had a higher mean age (N=9, mean = 74.20, SD = 7.73) than those who did not (N=113, mean = 62.01, SD = 12.99). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 12.19, which is a large effect size (d = 1.18). No other significant effects were found between carer age and signs within the "Physical signs" category or other subcategories.

No significant effects were found between carer knowledge of dementia and level of carer contact with their relative with dementia, and any sign from the "Physical signs" category.

Other signs

Tables 3.24, 3.25 and 3.26 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Other Signs" is explored.

Table 3.24: Effect of carer age on reporting of "Other signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Other signs reported	Yes	15	61.83	9.30	0.34	0.736
	No	107	63.06	13.52		
Informant report	Yes	6	59.14	9.05	0.722	0.472
	No	116	63.10	13.23		
Non-categorised	Yes	9	63.63	9.54	0.172	0.864
	No	113	62.85	13.32		

Table 3.25: Effect of carer knowledge of dementia on reporting of "Other signs" of dementia

	Sign reported	N (total = 101)	Mean quiz score (%)	SD	t	p
Other signs reported	Yes	13	58.08	16.78	0.25	0.812
	No	88	59.38	17.50		
Informant report	Yes	6	55.00	14.83	0.61	0.542
	No	95	59.47	17.51		
Non-categorised	Yes	7	60.71	19.02	0.237	0.813
	No	94	59.10	17.30		

Table 3.26: Effect of carer contact with relative with dementia age on reporting of "Other signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Other signs reported	Yes	9	10.81	8.72	0.07	0.945
	No	49	10.53	11.15		
Informant report	Yes	2	6.50	7.78	0.54	0.589
	No	56	10.72	10.85		
Non-categorised	Yes	7	12.04	9.13	0.38	0.705
	No	51	10.38	11.00		

Analysis indicates no significant effect of carer age, knowledge or level of contact with a relative with dementia on the reporting of "Other signs" of dementia.

For the purpose of analysis, relationship to person with dementia was transformed into the dichotomous variable spouse/non-spouse, and living situation was transformed into resident/not resident with the person with dementia. 2x2 chi-square tests were carried out to explore whether there was an association between the variables gender (male/female), relationship to person with dementia (spouse/non-spouse) and living situation (resident/non-resident), and each of the categories of first signs of dementia. The conditions which must be met to use a 2x2 chi-square are that: the data must be independent (no respondent can appear in more than one cell); no cell should have an expected frequency of less than 1; and no more than 20per cent of the expected frequencies in a table must have an expected frequency of less than 5 (Foster, 2001). If this last assumption is broken, the appropriate statistical test to use is Fisher's Exact Probability test (Dancey & Reidy, 2002). Fisher's does not have a value like χ^2 and is reported as a probability value only. Where Fisher's Exact Probability test is applied, this is highlighted in all chi-square results tables as "FEP, p = (value)".

Cognitive signs

Table 3.27 illustrates the results of analyses where the effect of carer gender, relationship to person with dementia and living situation on the reporting of categories and subcategories within "Cognitive Signs" is explored.

Table 3.27: Association between carer gender, relationship to person with dementia and living situation, and first signs reported within "Cognitive signs" category

2 x 2 Chi-square	Gender N = 122	Spouse/non-spouse N = 122	Resident/non-resident N = 122
Cognitive signs Reported	χ^2=0.424, df=1, p=0.515	χ^2=0.182, df=1, p=0.670	χ^2=0.832, df=1, p=0.362
Memory impairment (nos)	χ^2=0.593, df=1, p=0.441	χ^2=0.500, df=1, p=0.480	χ^2=0.047, df=1, p=0.829
Short term memory impaired	FEP, p = 0.349	FEP, p = 0.376	χ^2=0.585, df=1, p=0.444
Being forgetful	χ^2=0.820, df=1, p=0.775	χ^2=0.103, df=1, p=0.749	χ^2=0.349, df=1, p=0.555
Cognitive change	FEP, p = 0.295	FEP, p = 0.344	FEP, p 1.000
Executive function problems	FEP, p = 0.295	FEP, p = 1.000	FEP, p = 0.475
Language disorder	FEP, p = 1.000	FEP, p = 0.713	FEP, p = 0.476
Psychiatric phenomena	FEP, p = 1.000	FEP, p = 0.413	FEP, p = 0.682
Perseveration and repetition	χ^2=2.173, df=1, p=0.140	χ^2=0.385, df=1, p=0.535	χ^2=0.372, df=1, p=0.054
Being confused	FEP, p = 1.000	χ^2=0.709, df=1, p=0.400	χ^2=0.744, df=1, p=0.388

The results in Table 3.27 indicate no significant association between the first signs of dementia reported by carers in the "Cognitive Signs" category or related subcategories, and the variables gender, relationship to the person with dementia (spouse or non-spouse) and living situation (resident or non-resident with person with dementia).

Emotional signs

Table 3.28 illustrates the results of analyses where the effect of carer gender, relationship to person with dementia and living situation on the reporting of categories and subcategories within "Emotional Signs" is explored.

Table 3.28: Association between carer gender, relationship to person with dementia and living situation, and first signs reported within "Emotional signs" category.

2 x 2 Chi-square	Gender N = 122	Spouse/non-spouse N = 122	Resident/non-resident N = 122
Emotional signs reported	FEP, p = 1.000	FEP, p = 1.000	χ^2=0.232, df=1, p=0.630
Emotional change (nos)	FEP, p =0.318	FEP, p = 0.607	FEP, p = 1.000
Personality/ temperament change	FEP, p = 1.000	FEP, p = 1.000	FEP, p = 0.604
Depressed mood	FEP, p = 0.295	FEP, p = 1.000	FEP, p = 1.000
Anxiety	FEP, p = 0.505	FEP, p = 0.545	FEP, p = 1.000
Irritability/ hostility	FEP, p = 1.000	FEP, p =1.000	FEP, p = 0.345
Lack of emotional response/ lability	FEP, p = 1.000	FEP, p = 1.000	FEP, p = 1.000

The results in Table 3.28 indicate no significant association between the first signs of dementia reported by carers in the "Emotional Signs" category and related subcategories and the variables gender, relationship to the person with dementia (spouse or non-spouse) and living situation (resident or non-resident with person with dementia).

Behavioural signs

Table 3.29 illustrates the results of analyses where the effect of carer gender, relationship to person with dementia and living situation on the reporting of categories and subcategories within "Behavioural Signs" is explored.

Table 3.29: Association between carer gender, relationship to person with dementia and living situation, and first signs reported within "Behavioural signs" category.

2 x 2 Chi-square	Gender N = 122	Spouse/non-spouse N = 122	Resident/non-resident N = 122
Behavioural signs reported	**χ^2=4.602, df=1, p=0.032***	χ^2=0.001, df=1, p=0.970	χ^2=0.398, df=1, p=0.528
Behaviour change (nos)	FEP, p = 0.669	FEP, p = 1.000	FEP, p = 1.000
Withdrawal/ apathy	FEP, p = 1.000	FEP, p = 1.000	FEP, p = 0.059
Agitation and Restlessness	FEP, p = 0.669	FEP, p = 0.413	FEP, p = 0.211
Aggressive behaviour	FEP, p =1.000	FEP, p = 0.117	FEP, p = 0.497
Difficulty with purposeful tasks	FEP, p = 0.391	FEP, p = 0.764	χ^2=1.641, df=1, p=0.200
Disorientation/ getting lost	FEP, p = 0.722	FEP, p = 0.062	FEP, p = 0.496
Losing/ hoarding/ hiding things	χ^2=1.674, df=1, p=0.196	χ^2=1.393, df=1, p=0.238	χ^2=0.544, df=1, p=0.461
Self care abilities	FEP, p = 0.669	FEP, p = 0.092	FEP, p = 0.422
Social behaviour	FEP, p = 0.321	FEP, p = 0.656	FEP, p = 0.667

***p < 0.05**

The results in Table 3.29 indicate that there was a significant association between carer gender and the reporting of a sign within the main category of "Behavioural signs" (χ^2=4.602, df=1, p=0.032). Cramer's V, which is a measure of effect size, was 0.194, therefore nearly 4 per cent of the variation in the frequency of reporting within

this category can be explained by gender. Females reported a sign more often, and males less often, within this category than would be expected by chance. No other significant association was found to exist between the first signs of dementia reported by carers in the "Behavioural Signs" category and related subcategories, and the variables gender, relationship to the person with dementia (spouse or non-spouse) and living situation (resident or non-resident with person with dementia).

Physical signs

Table 3.30 illustrates the results of analyses where the effect of carer gender, relationship to person with dementia and living situation on the reporting of categories and subcategories within "Physical Signs" is explored.

Table 3.30: Association between carer gender, relationship to person with dementia and living situation, and first signs reported within "Physical signs" category.

2 x 2 Chi-square	Gender N = 122	Spouse/non-spouse N = 122	Resident/non-resident N = 122
Physical signs reported	χ^2=0.822, df=1, p=0.364	χ^2=0.278, df=1, p=0.598	χ^2=3.326, df=1, p=0.068
Physical change	FEP, p = 0.279	**FEP, p = 0.008***	**FEP, p = 0.034***
Nutritional concerns	FEP, p = 1.000	FEP, p = 0.550	FEP, p = 1.000
Mobility disturbances	FEP, p = 1.000	FEP, p = 0.344	FEP, p = 1.000
Sleep disturbance	FEP, p = 0.554	FEP, p = 0.550	FEP, p = 1.000
Continence	FEP, p = 0.295	FEP, p = 1.000	FEP, p = 1.000
Falls	FEP, p = 1.000	FEP, p = 1.000	FEP, p = 1.000

***p < .05**

The results in Table 3.30 indicate that there was a significant association between relationship to the person with dementia and the reporting of a sign within the subcategory of "Physical change non-specific". Since 25 per cent of cells had an expected frequency of less than 5, the appropriate test was Fisher's Exact Probability. This gave p=0.008 for a two-tailed hypothesis. Cramer's V was found to be 0.257, therefore nearly 7 per cent of the variation in the frequency of reporting within this category can be explained by relationship to the person with dementia. Spouse carers reported a sign more often, and non-spouse carers less often, within this category than would be expected by chance. There was also a significant association between living situation and the reporting of a sign within the subcategory of "Physical change non-specific". Since 50 per cent of cells had an expected frequency of less than 5, the appropriate test was Fisher's Exact Probability. This gave p=0.034 for a two-tailed hypothesis. Cramer's V was 0.206, therefore 4 per cent of the variation in the frequency of reporting within this category can be explained by the living situation of the carer and person with dementia. Carers who lived with their relative reported a sign more often, and non-resident carers less often, within this category than would be expected by chance.

No other significant association was found between the first signs of dementia reported by carers in the "Physical Signs" category and the variables carer gender, relationship to the person with dementia (spouse or non-spouse) and living situation (resident or non-resident with person with dementia).

Other signs

Table 3.31 illustrates the results of analyses where the effect of carer gender, relationship to person with dementia and living situation on the reporting of categories and subcategories within "Physical Signs" is explored.

Table 3.31: Association between carer gender, relationship to person with dementia and living situation, and first signs reported within "Other signs" category.

2 x 2 Chi-square	Gender N = 122	Spouse/non-spouse N = 122	Resident/non-resident N = 122
Other signs reported	FEP, p = 1.000	χ^2=3.371, df=1, p=0.066	χ^2=1.065, df=1, p=0.302
Informant report	FEP, p = 0.062	FEP, p = 0.663	FEP, p = 0.682
Non-categorised	FEP, p = 0.057	FEP, p = 0.162	FEP, p = 0.084

As can be seen in Table 3.31, no significant association was found between the first signs of dementia reported by carers in the "Other Signs" category and the variables gender, relationship to the person with dementia (spouse or non-spouse) and living situation (resident or non-resident with person with dementia).

3.3.2 Practitioner sample

Independent sample t-tests were carried out on practitioner data supplied prior to the training intervention being delivered to identify whether practitioner age, level of contact with patients with dementia and knowledge of dementia were related to first signs reported by practitioners. 2x2 chi-square tests were carried out on pre- and post-intervention data to identify whether the delivery of an educational intervention was

associated with change in the first signs of dementia reported by practitioners before and after training.

Cognitive signs

Tables 3.32, 3.33 and 3.34 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with people with dementia (pwd) on the reporting of categories and subcategories within "Cognitive Signs" is explored.

Table 3.32: Effect of practitioner age on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 178)	Mean age in years	SD	t	p
Cognitive signs reported	Yes No	163 15	44.68 40.69	8.81 7.22	1.70	0.090
Memory impaired (nos)	Yes No	66 112	45.56 43.63	9.09 8.48	1.43	0.155
Short term memory impaired	Yes No	60 118	43.53 44.76	7.48 9.31	0.88	0.378
Being forgetful	Yes No	40 138	44.59 44.27	9.26 8.61	0.20	0.842
Cognitive change	Yes No	18 160	41.83 44.63	10.23 8.54	1.29	0.199
Executive function problems	Yes No	18 160	41.10 44.71	8.33 8.73	1.68	0.095
Language disorder	Yes No	13 165	47.21 44.12	9.99 8.62	1.23	0.221
Psychiatric phenomena	Yes No	9 169	46.88 44.21	9.75 8.69	0.89	0.374
Perseveration and repetition	Yes No	12 166	47.66 44.10	8.12 8.75	1.36	0.174
Being confused	Yes No	50 128	44.73 44.19	7.58 9.17	0.37	0.714

Table 3.33: Effect of practitioner knowledge of dementia on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 201	Mean quiz score (%)	SD	t	p
Cognitive signs reported	Yes No	187 14	61.92 45.41	17.13 27.12	**3.32**	**0.001***
Memory impaired (nos)	Yes No	73 128	60.27 61.05	17.66 18.86	0.29	0.775
Short term memory impaired	Yes No	70 131	64.90 58.56	15.32 19.54	**2.35**	**0.020***
Being forgetful	Yes No	45 156	57.62 61.68	18.68 18.27	1.31	0.193
Cognitive change	Yes No	18 183	72.62 59.60	12.31 18.50	**2.92**	**0.004***
Executive function problems	Yes No	20 181	66.07 60.18	19.78 18.19	1.36	0.175
Language disorder	Yes No	15 186	61.43 60.71	16.38 18.59	0.14	0.885
Psychiatric phenomena	Yes No	12 189	66.07 60.43	14.65 18.59	1.03	0.304
Perseveration and repetition	Yes No	15 186	56.67 61.10	16.08 18.57	0.89	0.371
Being confused	Yes No	57 144	56.52 62.45	17.25 18.62	**2.08**	**0.039***

***p<.05**

Table 3.34: Effect of practitioner contact with people with dementia on reporting of "Cognitive signs" of dementia

	Sign reported	N (total = 137)	Mean contact (no./mth)	SD	t	p
Cognitive signs reported	Yes No	131 6	2.09 1.29	3.14 1.47	0.62	0.537
Memory impaired (nos)	Yes No	47 90	2.36 1.89	3.98 2.50	0.84	0.402
Short term memory impaired	Yes No	52 85	2.22 1.95	2.66 3.32	0.49	0.623
Being forgetful	Yes No	35 102	1.86 2.12	4.30 2.56	0.43	0.668
Cognitive change	Yes No	14 123	3.61 1.88	3.52 2.99	**2.01**	**0.046***
Executive function problems	Yes No	18 119	2.66 1.96	5.89 2.43	0.89	0.374
Language disorder	Yes No	12 125	2.00 2.06	1.91 3.18	0.06	0.949
Psychiatric phenomena	Yes No	9 128	3.42 1.96	8.11 2.43	1.38	0.171
Perseveration and repetition	Yes No	14 123	0.88 2.19	0.79 3.22	1.51	0.134
Being confused	Yes No	37 100	2.42 1.93	4.62 2.29	0.80	0.425

***p<.05**

The results of analyses indicate no statistically significant effect of practitioner age on the reporting of "Cognitive signs" of dementia.

Knowledge of dementia had a statistically significant effect on reporting signs within the main category 'Cognitive signs reported' and within subcategories "Short term memory impairment", "Cognitive change" and "Being confused". Practitioners who reported a sign within "Cognitive signs" had a higher mean quiz score (N = 187, mean = 61.92, SD = 17.13) than those who did not (N = 14, mean = 45.41, SD = 27.12). The mean difference between the 'Yes' and 'No' conditions for this category was 16.51, which is a large effect size (d = 0.75). Practitioners who reported a sign within "Short term memory impairment" had a higher mean quiz score (N = 70, mean = 64.90, SD = 15.32) than those who did not (N = 131, mean = 58.56, SD = 19.54). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 6.34, which is a small to medium effect size (d = 0.36). Practitioners who reported a sign within "Cognitive change" had a higher mean quiz score (N = 18, mean = 72.62, SD = 12.31) than those who did not (N = 183, mean = 59.60, SD = 18.50). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 13.02, which is a large effect size (d = 0.85). There was an inverse relationship between knowledge and reporting of a sign within the subcategory "Being confused". Practitioners who reported a sign in this subcategory had a lower mean quiz score (N = 57, mean = 56.52, SD = 17.23) than those who did not (N = 144, mean = 62.45, SD = 18.62). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 5.934, which is a small effect size (d = 0.33).

Contact with people with dementia had a statistically significant effect on reporting signs within the subcategory "Cognitive change". Practitioners who reported a sign within this subcategory had a higher mean number of contacts with people with dementia per week (N = 14, mean = 3.61, SD = 3.52) than those who did not (N = 123, mean = 1.88, SD = 2.99). The mean difference between the 'Yes' and 'No' conditions for this category was 1.73, which is a medium effect size (d = 0.53).

Emotional signs

Tables 3.35, 3.36 and 3.37 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with relative with dementia (non-cohabiting relative) on the reporting of categories and subcategories within "Emotional Signs" is explored.

Table 3.35: Effect of practitioner age on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 178)	Mean age in years	SD	t	p
Emotional signs reported	Yes	70	44.82	8.82	0.58	0.563
	No	108	44.04	8.71		
Emotional change (nos)	Yes	4	47.16	11.95	0.65	0.516
	No	174	44.28	8.68		
Personality/ temperament change	Yes	42	43.66	8.75	0.58	0.561
	No	136	44.56	8.76		
Depressed mood	Yes	24	44.46	8.18	0.07	0.944
	No	154	44.33	8.85		
Anxiety	Yes	7	44.88	7.47	0.16	0.871
	No	171	44.32	8.80		
Irritability/ hostility	Yes	4	44.94	10.77	0.14	0.890
	No	174	44.33	8.72		
Lack of emotion/ lability	Yes	3	51.43	11.18	1.42	0.157
	No	175	44.22	8.68		

Table 3.36: Effect of practitioner knowledge of dementia on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 201)	Mean quiz score (%)	SD	t	p
Emotional signs reported	Yes No	78 123	63.28 59.18	17.06 19.09	1.55	0.124
Emotional change (nos)	Yes No	5 196	61.43 60.75	10.83 18.56	0.08	0.935
Personality/ temperament change	Yes No	45 156	64.13 59.80	18.31 18.36	1.39	0.565
Depressed mood	Yes No	30 171	64.52 60.11	17.34 18.54	1.21	0.226
Anxiety	Yes No	10 191	70.00 60.28	18.69 18.30	1.63	0.104
Irritability/ hostility	Yes No	4 197	66.07 60.66	15.84 18.46	0.58	0.562
Lack of emotion/ lability	Yes No	3 198	59.52 60.79	4.12 18.53	0.12	0.906

Table 3.37: Effect of practitioner contact with people with dementia on reporting of "Emotional signs" of dementia

	Sign reported	N (total = 137)	Mean contact (no/mth)	SD	t	p
Emotional signs reported	Yes No	51 86	1.65 2.30	1.4 3.61	1.18	0.287
Emotional change (nos)	Yes No	4 133	1.75 2.06	1.24 3.12	0.20	0.842
Personality/ temperament change	Yes No	30 107	1.69 2.16	1.35 3.41	0.74	0.462
Depressed mood	Yes No	19 118	1.34 2.17	2.38 3.18	1.09	0.279
Anxiety	Yes No	8 129	1.47 2.09	1.48 3.16	0.55	0.581
Irritability/ hostility	Yes No	2 135	2.13 2.05	2.30 3.10	0.03	0.974
Lack of emotion/ lability	Yes No	1 136	No analysis possible			

The results of analyses indicate no statistically significant effect of practitioner age, knowledge of dementia or contact with people with dementia on the reporting of signs of dementia within the "Emotional signs" category and related subcategories.

Behavioural signs

Tables 3.38, 3.39 and 3.40 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with people with dementia on the reporting of categories and subcategories within "Behavioural Signs" is explored.

Table 3.38: Effect of practitioner age on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 178)	Mean age in years	SD	t	p
Behavioural signs reported	Yes	136	44.60	8.67	0.70	0.484
	No	42	43.52	8.99		
Behaviour change (nos)	Yes	41	43.43	8.96	0.77	0.446
	No	137	44.62	8.8		
Withdrawal/ apathy	Yes	5	46.99	10.45	0.69	0.493
	No	173	44.27	8.71		
Agitation and Restlessness	Yes	27	47.52	8.48	**2.069**	**0.040***
	No	151	43.78	8.69		
Aggressive behaviour	Yes	5	41.18	8.92	0.82	0.493
	No	173	44.44	8.80		
Difficulty with purposeful tasks	Yes	18	45.58	7.65	0.63	0.529
	No	160	44.21	8.86		
Disorientation/ getting lost	Yes	39	44.73	7.8	0.31	0.758
	No	139	44.24	8.96		
Losing/ hoarding/ hiding things	Yes	5	50.54	9.26	1.62	0.108
	No	173	44.17	8.68		
Self care abilities	Yes	49	45.29	7.86	0.89	0.375
	No	129	43.99	9.05		
Social behaviour	Yes	12	40.29	7.57	1.67	0.076
	No	166	44.64	8.76		

***p < .05**

Table 3.39: Effect of practitioner knowledge of dementia on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 201)	Mean quiz score (%)	SD	t	p
Behavioural signs reported	Yes No	153 48	61.91 57.14	16.1 22.30	1.57	0.118
Behaviour change (nos)	Yes No	45 156	62.86 60.17	16.16 18.99	0.86	0.388
Withdrawal/ apathy	Yes No	5 196	65.71 60.64	13.74 18.5	0.61	0.544
Agitation and Restlessness	Yes No	32 169	56.47 61.58	18.71 18.28	1.44	0.150
Aggressive behaviour	Yes No	7 194	45.92 61.30	20.97 18.13	**2.19**	**0.029***
Difficulty with purposeful tasks	Yes No	20 181	60.36 60.81	15.97 18.68	0.11	0.917
Disorientation/ getting lost	Yes No	43 158	59.80 61.03	16.57 18.90	0.39	0.698
Losing/ hoarding/ hiding things	Yes No	5 196	64.29 60.68	11.29 18.55	0.43	0.666
Self care abilities	Yes No	57 144	64.91 59.13	15.76 19.14	**2.03**	**0.044***
Social behaviour	Yes No	12 189	64.29 60.54	16.40 18.53	0.68	0.496

***p < 0.05**

Table 3.40: Effect of practitioner contact with people with dementia on reporting of "Behavioural signs" of dementia

	Sign reported	N (total = 137)	Mean contact (hrs/wk)	SD	t	p
Behavioural signs reported	Yes No	112 25	2.28 1.05	3.23 1.22	1.82	0.071
Behaviour change (nos)	Yes No	33 104	2.18 2.01	2.38 3.28	0.27	0.787
Withdrawal/ apathy	Yes No	4 133	4.06 1.99	5.70 2.99	1.33	0.187
Agitation and Restlessness	Yes No	21 116	1.44 2.17	1.19 3.30	0.99	0.323
Aggressive behaviour	Yes No	6 131	1.88 2.06	1.77 3.13	0.15	0.885
Difficulty with purposeful tasks	Yes No	14 123	3.72 1.87	3.06 3.04	**2.17**	**0.032***
Disorientation/ getting lost	Yes No	32 105	2.68 1.86	5.05	2.16	0.191
Losing/ hoarding/ hiding things	Yes No	5 132	6.60 1.88	10.30 2.41	**3.49**	**0.001***
Self care abilities	Yes No	42 95	1.60 2.26	1.57 3.54	1.15	0.254
Social behaviour	Yes No	10 127	3.63 1.93	7.61 2.43	1.68	0.084

Results of analyses show that age had a statistically significant effect on reporting signs within the subcategory "Agitation/restlessness". Practitioners who reported a sign within this category had a higher mean age (N=27, mean = 47.52, SD = 8.48) than those who did not (N=151, mean = 43.78, SD = 8.69). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 3.74, which is a medium effect size (d = 0.44). Age did not have a significant effect on reporting of the main category of "Behavioural signs" or the reporting of subcategories other than "Agitation/restlessness".

Practitioner knowledge of dementia had a statistically significant effect on reporting signs within the subcategory "Aggressive behaviour" (t = 2.19, DF = 120, p = 0.029). Practitioners who reported a sign within this category had a lower mean quiz score (N=7, mean = 45.92, SD = 20.97) than those who did not (N=194, mean = 61.30, SD = 18.13). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 15.39, which is a large effect size (d = 0.79). Practitioner knowledge also had a statistically significant effect on reporting signs within the subcategory "Self care abilities" (t = 2.02, DF = 120, p = 0.044). Practitioners who reported a sign within this category had a higher mean quiz score (N=57, mean = 64.91, SD = 15.76) than those who did not (N=144, mean = 59.13, SD = 19.14). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 5.79, which is a small effect size (d = 0.33).

Practitioner contact with people with dementia had a statistically significant effect on reporting signs within the subcategory "Difficulty with purposeful tasks" (t = 2.17, DF

= 120, p = 0.032). Practitioners who reported a sign within this category had a higher number of weekly contacts rate (N=14, mean = 3.72, SD = 3.06) than those who did not (N=123, mean = 1.87, SD = 3.04). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 1.86, which is a medium effect size (d = 0.61). Practitioner contact also had a statistically significant effect on reporting signs within the subcategory "Losing/hoarding/hiding things" (t = 3.49, DF = 120, p = 0.001). Practitioners who reported a sign within this category had a higher weekly contact rate (N=5, mean = 6.60, SD = 10.30) than those who did not (N=132, mean = 1.88, SD = 2.41). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 4.72, which is a large effect size (d = 0.74).

Physical signs

Tables 3.41, 3.42 and 3.43 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with people with dementia on the reporting of categories and subcategories within "Physical Signs" is explored.

Table 3.41: Effect of practitioner age on reporting of "Physical signs" of dementia

	Sign reported	N (total = 122)	Mean age in years	SD	t	p
Physical signs reported	Yes	23	47.73	9.93	**2.01**	**0.046***
	No	155	43.84	8.47		
Physical change (nos)	Yes	3	46.43	19.32	0.42	0.678
	No	175	44.31	8.56		
Nutritional concerns	Yes	6	54.51	8.37	**2.96**	**0.003***
	No	172	43.99	8.56		
Mobility disturbances	Yes	5	49.66	9.85	1.38	0.168
	No	173	44.19	8.69		
Sleep disturbance	Yes	4	46.08	6.98	0.40	0.690
	No	174	44.31	8.78		
Level of continence	Yes	8	42.47	6.72	0.49	0.628
	No	173	44.40	8.79		
Falls	Yes	3	43.45	8.43	0.18	0.859
	No	175	44.36	8.76		

***p < 0.05**

Table 3.42: Effect of practitioner knowledge of dementia on reporting of "Physical signs" of dementia

	Sign reported	N (total = 101)	Mean quiz score (%)	SD	t	p
Physical signs reported	Yes No	26 175	54.95 61.63	18.93 18.21	1.74	0.084
Physical change (nos)	Yes No	3 198	69.05 60.64	10.91 18.47	0.79	0.433
Nutritional concerns	Yes No	7 194	43.88 61.38	11.97 18.32	**2.51**	**0.013***
Mobility disturbances	Yes No	6 195	53.57 60.99	20.58 18.34	0.97	0.332
Sleep disturbance	Yes No	5 196	60.00 60.79	27.48 18.21	0.09	0.925
Level of continence	Yes No	6 195	55.95 60.92	18.30 18.42	0.65	0.506
Falls	Yes No	5 196	54.29 60.93	10.83 18.53	0.79	0.426

***p < .05**

Table 3.43: Effect of practitioner contact with relative with dementia age on reporting of "Physical signs" of dementia

	Sign reported	N (total = 58)	Mean contact (hrs/wk)	SD	t	p
Physical signs reported	Yes No	16 121	2.06 2.06	3.14 3.09	0.01	1.000
Physical change (nos)	Yes No	1 136	No analysis possible			
Nutritional concerns	Yes No	4 133	3.34 2.02	6.11 2.8	0.85	0.398
Mobility disturbances	Yes No	5 132	2.28 2.05	1.68 3.13	0.16	0.871
Sleep disturbance	Yes No	4 133	1.56 2.07	1.78 3.12	0.32	0.747
Level of continence	Yes No	3 134	1.08 2.08	1.23 3.11	0.55	0.583
Falls	Yes No	4 133	1.00 2.09	1.14 3.12	0.69	0.489

Age had a significant effect on reporting signs within the main category "Physical signs" ($t = 2.01$, $DF = 120$, $p = 0.046$) Practitioners who reported a sign within this category had a higher mean age (N=23, mean = 47.73, SD = 9.93) than those who did not (N=155, mean = 43.84, SD = 8.47). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 3.88, which is a medium effect size (d =

0.42). Age also had a significant effect on reporting signs within the subcategory "Nutritional concerns" (t = 2.96, DF = 120, p = 0.003). Practitioners who reported a sign within this category had a higher mean age (N=6, mean = 54.51, SD = 8.37) than those who did not (N=172, mean = 43.99, SD = 8.56). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 10.52, which is a large effect size (d = 1.24).

Knowledge had a significant effect on reporting signs within the subcategory "Nutritional concerns" (t = 2.51, DF = 120, p = 0.013). Practitioners who reported a sign within this category had a lower mean quiz score (N=7, mean = 43.88, SD = 11.97) than those who did not (N=194, mean = 61.38, SD = 18.32). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 17.50, which is a large effect size (d = 1.16).

No significant effects were found between level of practitioner contact and reporting of signs within the "Physical signs" category or related subcategories.

Other signs

Tables 3.44, 3.45 and 3.46 illustrate the results of analyses where the effect of age, knowledge of dementia and contact with people with dementia on the reporting of categories and subcategories within "Other Signs" is explored.

Table 3.44: Effect of practitioner age on reporting of "Other signs" of dementia

	Sign reported	N (total = 178)	Mean age in years	SD	t	p
Other signs reported	Yes	20	43.68	8.69	0.36	0.720
	No	158	44.43	8.77		
Informant report	Yes	13	43.44	8.11	0.39	0.668
	No	165	44.42	8.81		
Non-categorised	Yes	10	46.40	9.86	0.77	0.445
	No	168	44.22	8.68		

Table 3.45: Effect of practitioner knowledge of dementia on reporting of "Other signs" of dementia

	Sign reported	N (total = 201)	Mean quiz score (%)	SD	t	p
Other signs reported	Yes	22	63.64	15.09	0.77	0.440
	No	179	60.42	18.76		
Informant report	Yes	15	67.62	15.39	1.50	0.134
	No	186	60.22	18.48		
Non-categorised	Yes	10	57.86	7.86	0.51	0.609
	No	191	60.92	18.78		

Table 3.46: Effect of practitioner contact with people with dementia age on reporting of "Other signs" of dementia

	Sign reported	N (total = 137)	Mean contact (hrs/wk)	SD	t	p
Other signs reported	Yes	14	3.50	6.55	1.87	0.064
	No	123	1.89	2.40		
Informant report	Yes	8	2.63	2.58	0.54	0.592
	No	129	2.02	3.12		
Non-categorised	Yes	7	4.71	9.10	**2.40**	**0.019***
	No	130	1.91	2.40		

***p<0.05**

Level of practitioner contact with people with dementia had a significant effect on reporting signs within the subcategory "Non-categorised signs" (t = 2.38, DF = 199, p = 0.019). Practitioners who reported a sign within this category had a higher mean contact rate per week (N=7, mean = 4.71, SD = 9.70) than those who did not (N=130,

mean = 1.91, SD = 2.40). The mean difference between the 'Yes' and 'No' conditions for this subcategory was 2.80, which is a medium effect size (d = 0.46).

No significant effects were found between practitioner age or knowledge of dementia and reporting of signs within the "Other signs" category or related subcategories.

2x2 chi-square tests were carried out to explore whether there was a relationship between the variables gender (male/female), occupational discipline (GP or nurse) and relevant post-graduate training (yes or no) and each category and subcategory of first signs of dementia. As with carer data, the probability level was calculated and reported using Fisher's Exact Probability test for a two-tailed hypothesis if more than 20 per cent of cells had an expected probability of less than 5.

Cognitive signs

Table 3.47 illustrates the results of analyses where the effect of practitioner gender, occupational discipline and relevant post-graduate training on the reporting of categories and subcategories within "Cognitive Signs" is explored.

Table 3.47: Association between gender, occupational discipline and relevant post-graduate training, and first signs reported within "Cognitive signs" category.

2 x 2 Chi-square	Gender (male/female) N = 204	Discipline (GP/nurse) N = 204	Post-graduate training (Y/N) N = 204
Cognitive sign reported	χ^2=0.210, df=1, p=0.647	χ^2=0.004, df=1, p=0.950	χ^2=0.224, df=1, p=0.636
Memory impairment (nos)	χ^2=0.255, df=1, p=0.614	χ^2=0.394, df=1, p=0.530	χ^2=0.766, df=1, p=0.382
Short term memory impaired	χ^2=2.847, df=1, p=0.092	**χ^2=5.552, df=1, p=0.018***	χ^2=0.964, df=1, p=0.326
Being forgetful	**χ^2=4.438, df=1, p=0.035***	**χ^2=4.886, df=1, p=0.027***	χ^2=2.502, df=1, p=0.114
Cognitive change	χ^2=2.809, df=1, p=0.094	χ^2=0.914, df=1, p=0.339	χ^2=2.508, df=1, p=0.113
Executive function problems	χ^2=0.548, df=1, p=0.459	χ^2=0.430, df=1, p=0.512	χ^2=3.122, df=1, p=0.117
Language disorder	χ^2=0.429, df=1, p=0.513	χ^2=2.386, df=1, p=0.122	χ^2=2.791, df=1, p=0.095
Psychiatric phenomena	FEP, p = 0.755	FEP, p = 1.000	FEP, p = 1.000
Perseveration and repetition	FEP, p = 0.151	**χ^2=11.958, df=1, p=0.001***	χ^2=0.918, df=1, p=0.338
Being confused	**χ^2=6.160, df=1, p=0.013***	**χ^2=10.738, df=1, p=0.001***	**χ^2=4.759, df=1, p=0.029***

***p<0.05**

The results in Table 3.47 indicate a significant association between gender and the reporting of a sign within the subcategory "Being forgetful" (χ^2=4.438, df=1, p=0.035). Cramer's V was 0.147, therefore just over 2 per cent of the variation in the frequency of reporting within this category can be explained by gender. Females reported a sign more often, and males less often, within this subcategory than would be expected by chance. There was also a significant association between gender and the reporting of a sign within the subcategory "Being confused" (χ^2=6.160, df=1, p=0.013). Cramer's V was 0.174, therefore 3 per cent of the variation in the frequency of reporting within this category can be explained by gender. Females reported a sign more often, and males less often, within this subcategory than would be expected by chance.

There was a significant association between occupational discipline and the reporting of a sign within the "Short-term memory" subcategory (χ^2=5.552, df=1, p=0.018). Cramer's V was 0.165, therefore nearly 3 per cent of the variation in the frequency of reporting within this category can be explained by discipline. GPs reported a sign more often, and nurses less often, within this category than would be expected by chance. There was also a significant association between discipline and "Being forgetful" (χ^2=4.886, df=1, p=0.027). Cramer's V was 0.174, therefore just over 2 per cent of the variation in the frequency of reporting this sign can be explained by occupational discipline. Nurses reported this sign more often, and GPs less often, than would be expected by chance. There was a significant association between discipline and "Perseveration/ repetition" (χ^2=11.958, df=1, p=0.001). Cramer's V was 0.242, indicating that 6 per cent of the variation in the frequency of reporting this sign can be explained by occupational discipline. Nurses reported this sign more often, and GPs less often, than would be expected by chance. There was also a significant association between discipline and "Being confused" (χ^2=10.738, df=1, p=0.001). Cramer's V was 0.229, indicating that 5 per cent of the variation in the frequency of reporting this sign can be explained by occupational discipline. Nurses reported this sign more often, and GPs less often, than would be expected by chance.

There was a significant association between post-graduate training and "Being confused" (χ^2=4.759, df=1, p=0.029). Cramer's V was 0.153, indicating that just over 2 per cent of the variation in the frequency of reporting this sign can be explained by

relevant post-graduate training. Those with relevant post-graduate training reported this sign less often than would be expected by chance.

No other significant associations were found between the first signs of dementia reported by practitioners in the "Cognitive signs" category and related subcategories, and the variables gender, occupational discipline (GP/nurse) and relevant post-graduate training (yes/no).

Emotional signs

Table 3.48 illustrates the results of analyses where the effect of practitioner gender, occupational discipline and relevant post-graduate training on the reporting of categories and subcategories within "Emotional Signs" is explored.

Table 3.48: Association between gender, occupational discipline and relevant post-graduate training, and first signs reported within "Emotional signs" category and subcategories.

2 x 2 Chi-square	Gender (male/female) N = 204	Discipline (GP/nurse) N = 204	Post-graduate training (Y/N) N = 204
Emotional signs reported	χ^2=0.474, df=1, p=0.491	χ^2=0.003, df=1, p=0.958	χ^2=0.292, df=1, p=0.589
Emotional change	FEP, p = 0.331	FEP, p = 0.651	FEP, p = 0.373
Personality/ temperament change	χ^2=1.650, df=1, p=0.199	χ^2=0.176, df=1, p=0.675	χ^2=0.005, df=1, p=0.943
Depressed mood	χ^2=0.520, df=1, p=0.471	χ^2=0.387, df=1, p=0.534	χ^2=0.358, df=1, p=0.550
Anxiety	FEP, p = 0.730	FEP, p = 0.323	FEP, p = 0.744
Irritability/ hostility	FEP, p = 0.100	FEP, p = 1.000	FEP, p = 1.000
Lack of emotional response/ lability	FEP, p = 0.235	FEP, p = 0.288	FEP, p =0.055

The results in Table 3.48 indicate that no significant associations were found between the first signs of dementia reported by practitioners in the "Emotional signs" category and subcategories, and the variables gender, occupational discipline (GP/nurse) and relevant post-graduate training (yes/no).

Behavioural signs

Table 3.49 illustrates the results of analyses where the effect of practitioner gender, occupational discipline and relevant post-graduate training on the reporting of categories and subcategories within "Behavioural Signs" is explored.

Table 3.49: Association between gender, occupational discipline and relevant post-graduate training, and first signs reported within "Behavioural signs" category and subcategory.

2 x 2 Chi-square	Gender (male/female) N = 204	Discipline (GP/nurse) N = 204	Post-graduate training (Y/N) N = 204
Behavioural signs reported	χ^2=2.112, df=1, p=0.146	χ^2=0.087, df=1, p=0.768	χ^2=0.087, df=1, p=0.768
Behaviour change (non-specific)	**χ^2=3.857, df=1, p=0.050***	χ^2=3.272, df=1, p=0.070	χ^2=1.738, df=1, p=0.187
Withdrawal/ apathy	FEP, p = 0.659	FEP, p = 0.934	FEP, p = 0.651
Agitation/ restlessness	χ^2=0.310, df=1, p=0.578	**χ^2=5.216, df=1, p=0.022***	χ^2=0.239, df=1, p=0.625
Aggressive behaviour	FEP, p = 1.000	FEP, p = 0.431	FEP, p = 1.000
Difficulty with purposeful tasks	χ^2=0.071, df=1, p=0.790	χ^2=0.029, df=1, p=0.864	χ^2=0.637, df=1, p=0.425
Disorientation/ getting lost	χ^2=0.001, df=1, p=0.974	χ^2=0.039, df=1, p=0.844	χ^2=0.024, df=1, p=0.876
Losing/ hoarding/ hiding things	FEP, p = 0.177	FEP, p = 0.373	FEP, p = 0.934
Self care abilities	χ^2=1.974, df=1, p=0.160	χ^2=1.779, df=1, p=0.182	χ^2=0.003, df=1, p=0.995
Social behaviour	FEP, p = 0.344	FEP, p = 1.000	FEP, p = 0.379

***p<0.05**

The results in Table 3.49 indicate a significant association between gender and the reporting of a sign within the subcategory "Behaviour change non-specific" (χ^2=3.857, df=1, p=0.050). Cramer's V was 0.138, therefore 2 per cent of the variation in the frequency of reporting within this subcategory can be explained by gender. Males reported a sign more often, and females less often, within this subcategory than would be expected by chance. There was a significant association between occupational

discipline and the reporting of a sign within the subcategory "Agitation/restlessness" (χ^2=5.216, df=1, p=0.022). Cramer's V was 0.160, therefore nearly 3 per cent of the variation in the frequency of reporting within this category can be explained by occupational discipline. Nurses reported a sign more often, and GPs less often, within this subcategory than would be expected by chance.

No other significant associations were found to exist between the first signs of dementia reported by practitioners in the "Behavioural signs" category and subcategories, and the variables gender, occupational discipline (GP/nurse) and relevant post-graduate training (yes/no).

Physical signs

Table 3.50 illustrates the results of analyses where the effect of practitioner gender, occupational discipline and relevant post-graduate training on the reporting of categories and subcategories within "Physical Signs" is explored.

Table 3.50: Association between gender, occupational discipline and relevant post-graduate training, and first signs reported within "Physical signs" category and subcategories.

2 x 2 Chi-square	Gender (male/female) N = 204	Discipline (GP/nurse) N = 204	Post-graduate training (Y/N) N = 204
Physical signs reported	**χ^2=3.920, df=1, p=0.048***	χ^2=0.165, df=1, p=0.684	χ^2=0.209, df=1, p=0.647
Physical change (nos)	FEP, p = 1.000	FEP, p = 0.288	FEP, p = 1.000
Nutritional concerns	FEP, p = 0.432	FEP, p = 0.109	**FEP, p=0.045***
Mobility disturbance	FEP, p = 0.666	FEP, p = 0.410	FEP, p = 0.677
Sleep disturbance	FEP, p = 1.000	FEP, p = 0.651	FEP, p = 1.000
Level of continence	FEP, p = 0.666	FEP, p = 1.000	**FEP, p = 0.031***
Falls	FEP, p = 1.000	FEP, p = 1.000	FEP, p = 0.373

***p<0.05**

The results in Table 3.50 indicate a significant association between gender and the reporting of a sign within the main category "Physical signs" (χ^2=3.920, df=1, p=0.048). Cramer's V was 0.139, therefore 2 per cent of the variation in the frequency of reporting within this subcategory can be explained by gender. Females reported a sign more often, and males less often, within this subcategory than would be expected by chance.

There was a significant association between post-graduate training and the reporting of a sign within the subcategory "Nutritional concerns". Since 50 per cent of cells had an expected frequency of less than 5, the appropriate test was Fisher's Exact

Probability. This gave p=0.045 for a two-tailed hypothesis. Cramer's V was 0.148, therefore just over 2 per cent of the variation in the frequency of reporting within this subcategory can be explained by post-graduate training. There was also a significant association between training and reporting of a sign within the subcategory "Level of continence". Since 50 per cent of cells had an expected frequency of less than 5, the appropriate test was Fisher's Exact Probability. This gave p=0.031 for a two-tailed hypothesis. Cramer's V was 0.132, indicating that just below 2 per cent of the variation in the frequency of reporting within this subcategory can be explained by post-graduate training. Practitioners without relevant post-graduate training reported a sign more often, and those with relevant training reported less often, within this subcategory than would be expected by chance.

No other significant associations were found between the first signs of dementia reported by practitioners in the "Physical signs" category and subcategories, and the variables gender, occupational discipline (GP/nurse) and relevant post-graduate training (yes/no).

Other signs

Table 3.51 illustrates the results of analyses where the effect of practitioner gender, occupational discipline and relevant post-graduate training on the reporting of categories and subcategories within "Other Signs" is explored.

Table 3.51: Association between gender, occupational discipline and relevant post-graduate training, and first signs reported within "Other signs" category and subcategories.

2 x 2 Chi-square	Gender (male/female) N = 204	Discipline (GP/nurse) N = 204	Post-graduate training (Y/N) N = 204
Other signs reported	**χ^2=6.919, df=1, p=0.009***	χ^2=1.620, df=1, p=0.203	χ^2=0.302, df=1, p=0.583
Informant report	**FEP, p = 0.001***	**χ^2=6.832, df=1, p=0.009***	χ^2=1.563, df=1, p=0.211
Non-categorised	FEP, p = 0.750	FEP, p = 0.752	FEP, p = 0.537

***p<0.05**

The results in Table 3.51 indicate a significant association between gender and the reporting of a sign within the main category "Other signs" (χ^2=6.919, df=1, p=0.048). Cramer's V was 0.184, therefore just over 3 per cent of the variation in the frequency of reporting within this category can be explained by gender. Males reported a sign more often, and females less often, within this category than would be expected by chance. There was also a significant association between gender and the reporting of a sign within the subcategory "Informant report". Since 25 per cent of cells had an expected frequency of less than 5, the appropriate test was Fisher's Exact Probability. This gave p=0.001 for a two-tailed hypothesis. Cramer's V was 0.287, therefore 8 per cent of the variation in the frequency of reporting within this category can be explained by gender. Males reported a sign more often, and females less often, within this subcategory than would be expected by chance.

There was a significant association between occupational discipline and the reporting of a sign within the subcategory "Informant report" (χ^2=6.832, df=1, p=0.009). Cramer's

V was 0.183, therefore just over 3 per cent of the variation in the frequency of reporting within this category can be explained by occupational discipline. GPs reported a sign more often, and nurses less often, within this subcategory than would be expected by chance.

No other significant associations were found to exist between the first signs of dementia reported by practitioners in the "Other signs" category and related subcategories, and the variables gender, occupational discipline (GP/nurse) and relevant post-graduate training (yes/no).

3.3.3 Comparison of carer and practitioner samples

A 2x2 Chi-square analysis of the proportion of carers and practitioners who reported a sign within each category and subcategory of first signs of dementia was carried out to identify whether there was a significant difference between the proportions of participant type reporting within each category and subcategory.

Cognitive signs

Table 3.52:Association between type of participant (carer or practitioner) and first signs reported within "Cognitive signs" category and related subcategories.

2 x 2 Chi-square	N in each group who reported sign		χ^2	p	Cramer's V	Per cent variation attributable to type of participant
	Carers (N=122)	Practitioners (N = 204)				
Cognitive sign reported	90	188	20.555	**0.001***	0.251	6 per cent
Memory impairment (nos)	22	73	11.655	**0.001***	0.189	4 per cent
Short term memory impaired	14	70	20.818	**0.001***	0.253	13 per cent
Being forgetful	43	46	6.201	**0.013***	0.138	2 per cent
Cognitive change	1	18	8.911	**0.003***	0.165	3 per cent
Executive function problems	1	29	10.225	**0.001***	0.177	3 per cent
Language disorder	8	16	0.185	0.667	---	---
Psychiatric phenomena	6	12	0.136	0.712	---	---
Perseveration/ repetition	21	15	7.556	**0.006***	0.152	2 per cent
Being confused	16	57	9.657	**0.002***	0.172	3 per cent

***p <0.05**

The results in Table 3.52 indicate a significant association between participant type (carer or practitioner) and reporting of a sign within the "Cognitive signs" category, and within the subcategories "Memory impairment non-specific", "Short term memory impairment", "Executive function problems" and "Being confused". More practitioners and fewer carers than would be expected by chance reported a sign within these categories/subcategories. There was also a significant association between the reporting of a sign within the subcategories "Being forgetful" and

"Perseveration and repetition", with more carers and fewer practitioners than would be expected by chance reporting a sign within these subcategories. There was no significant association between the type of participant and the subcategories of "Language disorder" and "Psychiatric phenomena".

Emotional signs

Table 3.53:Association between type of participant (carer or practitioner) and first signs reported within "Emotional signs" category and related subcategories. ***p <0.05**

2 x 2 Chi-square	N in each group who reported sign		χ^2	p	Cramer's V	Per cent variation attributable to type of participant
	Carers (N=122)	Practitioners (N=204)				
Emotional signs reported	13	78	28.858	**0.001***	0.298	9 per cent
Emotional change (nos)	4	5	FEP	0.732	---------	----------
Personality/ temperament change	3	45	23.357	**0.001***	0.268	7 per cent
Depressed mood	1	30	17.108	**0.001***	0.229	5 per cent
Anxiety	2	10	FEP	0.732	--------	----------
Irritability/ hostility	4	4	FEP	0.478	--------	----------
Lack of emotional response/ lability	4	3	FEP	0.431	----------	----------

*** p < .05**

The results in Table 3.53 indicate a significant association between participant type (carer or practitioner) and reporting of a sign the main category of "Emotional signs", and within the subcategories "Personality and temperament" and "Depressed mood". More practitioners and fewer carers than would be expected by chance reported a sign within these areas. There was no significant association between the type of participant (carer or practitioner) and the subcategories of " Emotional change non-

specific", "Irritability/ hostility", "Anxiety" and "Lack of emotional response/lability".

Behavioural signs

Table 3.54. Association between type of participant (carer or practitioner) and first signs reported within "Behavioural signs" category and related subcategories.

2 x 2 Chi-square	N in each group who reported sign		χ^2	p	Cramer's V	Per cent variation attributable to type of participant
	Carers (N=122)	Practitioners (N=204)				
Behavioural signs reported	52	154	35.456	**0.001***	0.330	11 per cent
Behaviour change (nos)	6	45	16.997,	**0.001***	0.228	5 per cent
Withdrawal/ apathy	5	5	FEP	0.510	--------	----------
Agitation/ restlessness	6	32	8.596	**0.003***	0.162	3 per cent
Aggressive behaviour	2	7	FEP	0.492	--------	----------
Difficulty with purposeful tasks	13	20	0.061	0.815	--------	----------
Disorientation/ getting lost	9	43	10.690	**0.001***	0.181	3 per cent
Losing/ hoarding/ hiding things	18	5	17.622	**0.001*.**	0.233	5 per cent
Self care abilities	6	58	26.752	**0.001***	0.286	8 per cent
Social behaviour	5	12	0.447	0.504	----------	----------

***p < .05**

The results in Table 3.54 indicate a significant association between participant type (carer or practitioner) and reporting of a sign within the category "Behavioural signs", and within the subcategories "Behaviour change non-specific", "Agitation and restlessness", "Disorientation /getting lost" and "Self care abilities". More practitioners and fewer carers than would be expected by chance reported a sign within these categories/subcategories. There was also a significant association

between reporting of a sign within the subcategory "Losing/hoarding/hiding things". More carers and fewer practitioners than would be expected by chance reported a sign within this subcategory. There was no significant relationship between the type of participant and the subcategories "Withdrawal/ apathy", "Aggressive behaviour", "Difficulty with purposeful tasks" and "Social behaviour".

Physical signs

Table 3.55: Relationship between type of participant (carer or practitioner) and first signs reported within "Physical signs" category and related subcategories.

2 x 2 Chi-square	N in each group who reported sign		χ^2	p	Cramer's V	Per cent variation attributable to type of participant
	Carers (N=122)	Practitioners (N=204)				
Physical signs reported	23	26	2.230	0.135	--------	----------
Physical change (nos)	9	3	FEP	**0.011***	0.152	2per cent
Nutritional concerns	3	7	FEP	0.749	--------	----------
Mobility disturbances	1	6	FEP	0.263	--------	----------
Sleep disturbance	3	5	FEP	1.000	--------	----------
Level of continence	1	6	FEP	0.263	--------	----------
Falls	8	5	FEP	0.082	--------	----------

***p <0.05**

As indicated in Table 3.55 there was a significant association between participant type (carer or practitioner) and reporting of a sign within the subcategory "Physical change non-specific". More carers and fewer practitioners than would be expected by chance reported a sign within this subcategory. No other significant associations were noted between the type of participant and the main category of "Physical signs" or the

subcategories of "Nutritional concerns", "Mobility disturbance", "Sleep disturbance", "Level of continence" or "Falls".

Other signs

Table 3.56: Association between type of participant (carer or practitioner) and first signs reported within "Other signs" category and subcategories.

2 x 2 Chi-square	N in each group who reported sign		χ^2	p	Cramer's V	Per cent variation attributable to type of participant
	Carers (N=122)	Practitioners (N=204)				
Other signs reported	15	23	0.077	0.781	----------	----------
Informant report	6	15	0.751	0.386	----------	----------
Non-categorised	9	11	0.522	0.470	----------	----------

The results in Table 3.56 indicate that no significant association was found between the type of participant (carer or practitioner) and the main category of "Other signs" or the subcategories of "Informant report" or "Non-categorised other signs".

3.3.4 Comparison of practitioner responses pre-and post-intervention

2x2 chi-square tests were carried out to identify whether the delivery of an educational intervention had an observable effect on first signs of dementia reported by practitioners before and after training. The number of practitioners remaining in the study at the post-intervention stage (referred to as T2) was smaller than at the pre-intervention stage (referred to as T1) due to a high degree of attrition post-intervention from the original sample. Twenty-three practitioners had left their post and moved to a

practice outwith the study area. Four refused to complete the questionnaire due to time constraints and 46 did not return it before the end date of the study, for reasons unknown to the original study team. One hundred and forty one practitioners returned a questionnaire, however 17 had not completed the questions on first signs of dementia, leaving 124 questionnaires fully completed. Of these, 35 belonged to the control group of practices who had not received training, leaving a total of 89 practitioner questionnaires available for pre-post training analysis. The responses to the question on first signs of dementia made in the post-intervention questionnaire (at T2) were compared to those made on the pre-intervention questionnaire (at T1).

Cognitive signs

Table 3.57: Association between pre- and post-intervention reporting of first signs within "Cognitive signs" category and subcategories.

2 x 2 Chi-square	Pre- post-intervention comparison N = 89	Cramer's V	per cent variation attributable to pre-post status
Cognitive sign reported	FEP, p = 1.000	------	------
Memory impairment (nos)	χ^2=3.295, df=1, p=0.069	-----	-----
Short term memory impaired	**χ^2=4.326, df=1, p=0.038***	0.220	5 per cent
Being forgetful	FEP, p = 0.221	-----	------
Cognitive change	FEP, p = 0.113	-----	-----
Executive function problems	**FEP, p = 0.039***	0.311	9 per cent
Language disorder	FEP, p = 1.000	----	-----
Psychiatric phenomena	FEP, p = 0.277	----	-----
Perseveration/ repetition	FEP, p = 0.161	----	-----
Being confused	**χ^2=5.132, df=1, p=0.023***	0.218	5 per cent

***p < .05**

The results in Table 3.57 indicate that there was a statistically significant difference in the number of practitioners who had received a training intervention reporting a sign within the "Short term memory impairment", "Executive function" and "Being confused" subcategories. Practitioners reported signs within these categories statistically more often at T1 (pre-intervention) than at T2 (post-intervention).

Emotional signs

Table 3.58: Association between pre- and post-intervention reporting of first signs within "Emotional signs" category and subcategories.

2 x 2 Chi-square	Pre- post-intervention comparison N = 89	Cramer's V	per cent variation attributable to pre-post status
Emotional signs reported	**χ^2=11.139, df=1, p=0.001***	0.354	12 per cent
Emotional change (nos)	FEP, p = 1.000	---------	----------
Personality/ temperament change	**χ^2=5.206, df=1, p=0.023***	0.242	6 per cent
Depressed mood	FEP, p = 0.497	-----	----
Anxiety	FEP, p = 1.000	-----	----
Irritability/ hostility	FEP, p = 1.000	--------	----------
Lack of emotional response/ lability	FEP, p = 0.131	----------	----------

***p <0.05**

The results in Table 3.58 indicate that there was a significant difference in the number of practitioners reporting a sign within the "Emotional signs" category, and the "Personality/temperament change" subcategory between T1 and T2. More practitioners reported a sign within these categories at post-intervention stage than at pre-intervention. No significant differences were found between T1 and T2 for the other subcategories.

Behavioural signs

Table 3.59: Association between pre- and post-intervention reporting of first signs within "Behavioural signs" category and subcategories.

2 x 2 Chi-square	Pre- post-intervention comparison N = 89	Cramer's V	Per cent variation attributable to pre-post status
Behavioural signs reported	FEP, p = 0.546	-----	-----
Behaviour change (nos)	**χ^2=11.286, df=1, p=0.001***	0.356	12 per cent
Withdrawal/ apathy	FEP, p = 1.000	--------	----------
Agitation/restlessness	**FEP, p = 0.005***	0.347	12 per cent
Aggressive behaviour	FEP, p = 1.000	--------	----------
Difficulty with purposeful tasks	FEP, p = 0.336	--------	----------
Disorientation/ getting lost	FEP, p = 1.00	--------	----------
Losing/ hoarding/ hiding things	No practitioners reported at T2	-------	----------
Self care abilities	**χ^2=5.072, df=1, p=0.024***	0.239	6 per cent
Social behaviour	FEP, p = 1.000	----------	----------

***p <0.05**

The results in Table 3.59 indicate that there was a significant difference in the number of practitioners reporting a sign within the "Behaviour change nos" subcategory. Fewer practitioners reported a sign within this subcategory at T2 than T1. There was a statistically significant difference in the number of practitioners reporting a sign within the "Agitation/restlessness" and "Self care abilities" subcategories. More practitioners reported a sign within these subcategories at T2 than at T1. No other significant differences were found between T1 and T2 for the main category of "Behaviour signs" or other subcategories.

Physical signs

Table 3.60: Association between pre- and post-intervention reporting of first signs within "Physical signs" category and subcategories.

2 x 2 Chi-square	Pre- post-intervention comparison N = 89	Cramer's V	per cent variation attributable to pre-post status
Physical signs reported	**FEP, p=0.015***	0.297	9per cent
Physical change (nos)	FEP, p = 1.000	--------	----------
Nutritional concerns	FEP, p = 0.099	--------	----------
Mobility disturbances	No subjects reported within subcategory at T2	--------	----------
Sleep disturbance	FEP, p = 1.000	--------	----------
Level of continence	FEP, p = 0.110	--------	----------
Falls	FEP, p = 1.000	--------	----------

***p < .05**

The results in Table 3.60 indicate a significant difference between the signs reported within the "Physical signs" category between T1 and T2. Fewer practitioners reported a sign within this category at T2 than at T1. No significant differences were found between T1 and T2 for any subcategories within the "Physical signs" category.

Other signs

Table 3.61 Association between pre- and post-intervention reporting of first signs within "Other signs" category and subcategories.

2 x 2 Chi-square	Participant type (carer or practitioner) N = 326	Cramer's V	per cent variation attributable to pre-post status
Other signs reported	FEP, p = 0.495	----------	----------
Informant report	FEP, p = 0.397	----------	----------
Non-categorised	FEP, p = 1.000	----------	----------

The results in Table 3.61 indicate that there were no significant differences between the signs reported within the "Other signs" category or related subcategories between T1 and T2.

4 Discussion

This section will begin by presenting the aims of the present research. A summary of the main findings of the research will then be provided, followed by suggestions of implications for clinical practice. Methodological issues will be discussed before making suggestions towards future research in this area. Concluding remarks will be given.

4.1 Aims of the Present Research

The stated aims of the present study were:

- To explore the perceptions of the first signs of dementia of informal carers of people with dementia, and of primary health care practitioners involved in the diagnosis and management of dementia.

- To explore whether training in the diagnosis and management of dementia had an impact on primary care practitioners' perceptions of the first signs of dementia.

- To explore the impact of sociodemographic and occupational factors on the first signs of dementia reported by carers and practitioners.

The profile of the sample was compared to previous studies within the area of dementia research. The results were considered with reference to the four research questions. As this was an exploratory study, it was considered important to detect any possible differences in order to guide future research.

4.2 Summary of the Main Findings

4.2.1 Sample profile

Around 70 per cent of people with dementia living in the community live with their carer. Most carers in the present study were the spouse (34.4 per cent) or daughter (32.8 per cent) of the person with dementia. This is comparable with the carer profile of samples from previous studies (LaRue *et al*, 1993; Gonzalez *et al*, 1999; Alzheimer's Scotland, 2000; Downs *et al*, 2003). The sample in this study can therefore be considered representative of carers of people with dementia.

4.2.2 Concordance about the first signs of dementia

Research question 1

> Is there concordance between carers and Primary Care practitioners about the first signs of dementia?

The results indicate significant differences in the type of sign reported by carers and practitioners. Carers were statistically more likely to report "Forgetfulness" and "Perseveration/repetition", whereas practitioners were more likely to report "Memory

impairment not otherwise specified", "Short term memory problems", "Being confused" and "Executive function problems" within the "Cognitive signs" category. Carers were statistically more likely to report the behavioural sign "Losing/ hoarding/hiding things", whereas practitioners reported "Agitation", "Disorientation/getting lost", "Self-care abilities" and "Behavioural change not otherwise specified" statistically more often than carers did within the "Behavioural signs" category. Carers were statistically less likely to report "Emotional signs" than practitioners, in particular "Depressed mood" and "Personality/temperament change". Carers were statistically more likely to report "Physical change not otherwise specified" than practitioners.

These results appear to indicate that whilst carers do report signs within the same overall categories as practitioners, they express their concerns using different language. They are much more likely to use language such as "forgetfulness" to describe their relative's failing memory than to use language such as "loss of memory for recent events", as practitioners did. Carers also report signs that are specific to their relative, as this is often their only hands-on experience of dementia, whereas practitioners report general signs based on their experience of a number of cases they may have dealt with. Therefore, carers reported signs such as "forgetting what I was saying to him" and "forgets things that have happened recently", whereas practitioners reported signs such as "reported forgetfulness" within the same subcategory of forgetfulness. Practitioners generally used medically orientated concepts to describe signs of dementia, whereas carers used specific events as indicators that something was wrong. This may explain the finding that carers report signs such as losing,

hoarding and hiding things significantly more often than practitioners. For example, a fairly typical example of one carers response was that she noticed "items going missing in the house e.g. cutlery going in the bin", whereas practitioners responses were more vague, such as "misplacing objects". Carers were also more likely to explain first signs of dementia through changes in their relatives' normal routine, such as "buying the same things in the shops repeatedly" rather than to generalise this to all behaviour as practitioners tended to do in their responses e.g. "repetitive behaviour".

4.2.3 Carers reported perceptions of the first signs of dementia

Research question 2

> Do age, gender, knowledge of dementia, relationship to the person with dementia and living situation have an effect on carers' reported perceptions of the first signs of dementia?

Results indicate that age had no significant effect on the reporting of cognitive signs, emotional signs, or other non-categorised signs of dementia. It did have an effect on the reporting of signs within the "Disorientation/getting lost" subcategory of behavioural signs, in that carers who reported a sign within this subcategory were older, on average, than those who did not. However, as there were a small number of carers in the 'yes' condition for this subcategory (N =13), caution must be taken in interpreting this result. It may indicate some effect of age, but further research would be needed to validate this. Carers who reported a sign within the subcategory 'Physical change not otherwise specified' were also, on average, older than those who

did not. Caution is however needed when interpreting this result because of the small number of respondents in the 'yes' condition (N = 9). It is possible that older carers may be more likely to report these signs since they tend to be spouses of people with dementia, and are more likely to be living with the older person and more aware of changes in their physical and psychological state. It is therefore important to note that these results may be more related to the relatives' proximity to the person with dementia rather than their age.

There was no significant effect of contact with their relative with dementia amongst non-cohabiting carers on the reporting of "Cognitive signs", "Physical signs" or "Other signs" of dementia. Contact did have an observable effect on reporting signs within the subcategory 'Personality/temperament change'. Carers who reported a sign within this subcategory had more contact with their relative per week than those who did not. This would appear to make sense, since greater contact gives greater opportunity to spot change. However, as the number of respondents in the 'yes' condition for this subcategory was only two, the significance of this result is questionable. Contact may be a factor in noticing change in a relative with dementia's personality or temperament but further research would be needed to validate this. Contact had a significant effect on the reporting of signs within the subcategory "Losing/hoarding/hiding things". Again, it would appear to make sense that greater contact would give greater opportunity to witness this behavioural change. Carers within the 'yes' condition for this sign (N = 18) had twice the amount of contact per week with their relative than those who did not report this sign.

Knowledge of dementia had no significant effect on the reporting of "Emotional signs", "Physical signs" or "Other signs" of dementia. It did have a significant effect on reporting signs within the subcategory "Being confused". Carers who reported a sign within this category scored higher on a measure of knowledge of dementia than those who did not. Carer knowledge of dementia also had a significant effect on reporting signs within the subcategory 'Self care abilities'. Carers who reported a sign within this category scored higher on a measure of knowledge than those who did not. It would appear at first sight that having greater knowledge of dementia helps carers to spot early signs. However, it is possible that knowledge of dementia gained since a relatives' diagnosis has made participants more aware of the signs of dementia and therefore more likely to report them. As with all retrospective clinical studies, researchers are reliant on the memory of respondents, which may or may not reliably recall information and which may be affected by subsequent knowledge gains.

There was a significant association between gender and the reporting of a sign within the main category of "Behavioural signs". Females reported a sign within this category four times as often as males. This is an interesting finding, given that one of the known reasons for increased carer stress is an increased level of behavioural problems, particularly aggression, displayed by the person with dementia. It is possible that females report this sign more often because they find behavioural problems more difficult to deal with, or more stressful to manage than males. Further research is necessary to clarify the reasons for this finding. Gender was not significantly associated with reporting of first signs of dementia within other categories and subcategories.

Relationship to the person with dementia was significantly associated with reporting of a sign within the subcategory of "Physical change not otherwise specified". Of those who reported a sign within this subcategory, 78 per cent were spouses and 22 per cent were not. This may relate to the earlier point that spouse carers tend to live with their relative and therefore have more contact and perhaps knowledge of their relatives' physical state. This possibility is strengthened by the finding that there was also a significant relationship between living situation and the reporting of a sign within the subcategory of "Physical change not otherwise specified". Seventy per cent of carers who reported a sign within this category lived with their relative. No other significant relationships were found between relation to the person with dementia and reporting of first signs of dementia.

4.2.4 Practitioners reported perceptions of the first signs of dementia

Research question 3

> Does age, gender, knowledge of dementia, occupational discipline and previous experience of dementia have an effect on practitioners' reported perceptions of the first signs of dementia?

There was no significant effect of age on the reporting of "Cognitive signs" or "Emotional signs" of dementia amongst practitioners. Within the "Behavioural signs" category, age had a significant effect on reporting signs within the subcategory "Agitation/restlessness". Practitioners who reported a sign within this category were,

on average, four years older than those who did not. Age also had a significant effect on reporting signs within the main category "Physical signs" and within the subcategory "Nutritional concerns". Again, practitioners who reported a sign within this category and subcategory were, on average, older than those who did not. These findings could possibly reflect differences in training for older practitioners, or a greater number of years of experience with people with dementia. Observation of changes in behaviour such as agitation is recognised as a valid first sign of dementia, which may precede other observable changes (Eccles *et al.*, 1998).

Knowledge of dementia had a significant effect on reporting signs within the main category 'Cognitive signs reported' and within subcategories "Short term memory impairment", and "Cognitive change". Practitioners who reported a sign within these categories had a higher score on a measure of knowledge about dementia than those who did not. Practitioners who reported a sign in the "Being confused" subcategory had a lower score on the same measure than those who did not. These findings may reflect the traditional focus of medical training on biological changes, as cognitive change in dementia is viewed by GPs as a reflection of neurobiological change. It is perhaps not surprising that 'being confused' was used more often by those with less knowledge as the term has made its way into common everyday language.

Practitioner knowledge had a significant effect on reporting signs within the subcategory "Aggressive behaviour". Those with a lower knowledge score reported this sign more often than those who did not. This may reflect the experience of practitioners who may traditionally have only become involved with people with

dementia when management of behavioural problems became an issue. Knowledge also had a statistically significant effect on reporting signs within the subcategory "Self care abilities". Practitioners who reported a sign within this category had a higher knowledge score than those who did not. This may be recognised by practitioners as a first sign because carers tend to voice it as a concern, and it is often visibly in evidence to others, especially if the practice team are involved in visiting the person with dementia in their own home. Knowledge had a significant effect on reporting signs within the subcategory 'Nutritional concerns'. Practitioners who reported a sign within this category had a lower knowledge score than those who did not. Whilst obviously speculative, one possible explanation for this finding may be that it reflects the use of general medical screening tactics amongst those with less knowledge of specialist assessment of dementia (which, of course, is not to say that nutritional concerns are not an important issue for people with dementia).

Contact with people with dementia had a significant effect on reporting "Cognitive change", "Losing/hoarding/hiding things", 'Non-categorised signs' and 'Difficulty with purposeful tasks'. Practitioners who reported a sign within these subcategories had more contacts in a week with people with dementia than those who did not. It would appear that having more contact with people with dementia does benefit the practitioner in that they are better able to spot behavioural and cognitive change. This has obvious benefits for the person with dementia and their family, since early identification of difficulties can result in a proactive, rather than reactive, response from practitioners. The research previously discussed highlights how important early

identification, diagnosis and therapeutic intervention are for people with dementia and their families, and also that it is desired by them.

Gender was significantly associated with reporting of a sign within the subcategories "Being forgetful" and "Being confused". Females reported a sign more often than males within these subcategories. This may reflect the gender breakdown of the sample, as these subcategories were used more by nursing staff, the majority of whom were female, than by doctors. There was a significant relationship between gender and the reporting of a sign within the subcategory "Behaviour change non-specific". Males reported a sign more often, and females less often, within this subcategory. Possible reasons for this finding are not clear, although it may reflect a difference in the way females and males, or perhaps nurses and GPs, conceptualise and classify behavioural change. Further research into how these groups classify behavioural change would perhaps highlight the reasons for this finding. There was also a significant association between gender and the reporting of "Physical signs". Females reported a sign more often, and males less often, within this subcategory. Again, it is possible to speculate that this may reflect the gender breakdown of the sample in that the nurses, the majority of whom were female, were more likely to be involved in the physical care, rather than the diagnosis and assessment, of people with dementia.

Within the "Cognitive signs" category, there was a significant association between occupational discipline and the reporting of a sign within the "Short-term memory" subcategory. GPs reported a sign more often than nurses in this subcategory. There was also a significant association between discipline and use of terms, "Being

forgetful", "Perseveration/ repetition" and "Being confused". Nurses reported signs within these subcategories more often than GPs. Within the "Behavioural signs" category, there was a significant association between occupational discipline and the reporting of "Agitation/restlessness" Nurses reported a sign more often than GPs within this subcategory. This may reflect the increased time available to nurses to spend with their patients, such as on home visits, in comparison to the 7-10 minute appointment time allocated to a GP in surgery. There was a significant association between occupational discipline and the reporting of a sign within the subcategory "Informant report". GPs reported a sign within this subcategory more often than nurses. It is possible that due to their limited contact with relatives and their limited time available to see patients, they consider an informant report helpful in developing a fuller picture on which to base a diagnosis or specialist referral. It is encouraging that GPs consider informant reports important in assessing the first signs of dementia since it is widely recognised that carers are good informants, good at noticing change in their relative, effective managers of care and as entitled to support as the person with dementia they care for (Eccles *et al*, 1998; Audit Commission, 2000, 2002, 2004; Department of Health, 2001).

There was a significant association between post-graduate training and "Being confused". Those with relevant post-graduate training reported this sign less often than those without. There was also significant association between post-graduate training and the reporting of signs within the "Nutritional concerns" and "Level of continence" subcategories. Practitioners without relevant post-graduate training reported a sign more often within these subcategories than practitioners who had

completed training. It is possible that those with post-graduate training are more likely to report specific medical signs, such as "Short term memory" and less likely to report general physical signs if they have received training in identifying specific diagnostic indicators. It is also possible that their training may have focused purely on the cognitive indicators of dementia, or on the generalised signs of dementia of all types, such as memory impairment.

4.2.5 The effect of training on reporting of first signs

Research question 4

> Does training in the diagnosis and management of dementia for Primary Care practitioners have an effect on their perceptions of the first signs of dementia?

As in any study involving pre-and post-intervention data collection, attrition of subjects from the study raises the possibility of response bias, in that those leaving the study may have had a different response to the interventions than those remaining. It is possible, in this instance, to carry out an "intention to treat" analysis. This procedure is essentially cautious, as it assumes that no benefit has accrued to those for whom Time 2 data are missing. As this was an exploratory study, it was important to look for any significant differences in order to highlight areas worthy of further investigation and to guide future research. An "intention to treat" analysis was therefore not considered to be a useful measure. Therefore, within this study, only practitioners who had completed the intervention and returned post-intervention measures were included in pre-post intervention analysis.

At the post-intervention stage i.e. after receiving training, practitioners reported signs less often within the "Short term memory impairment", "Executive function", "Being confused" and "Behaviour change nos" subcategories, and within the "Physical signs" category, than they had prior to training. More practitioners reported a sign within the category of "Emotional signs" and the "Personality/temperament change", "Agitation/ restlessness" and "Self care abilities" subcategories following training than before receiving training. These changes in reporting of signs may indicate that practitioners had gained some benefit from training in that their knowledge of good practice guidelines, delivered through the training interventions, had improved. This may be indicated by the increase in reporting of "Emotional signs" and more specific behavioural indicators such as "Personality/temperament change" and "Agitation/ restlessness" as early signs of dementia. Eccles *et al* (1998) and the SIGN guidelines (1998; 2006) highlight that behavioural change may appear before observable cognitive change, and this was highlighted in the training interventions. It may therefore be possible to affect practitioners' perception of what the first signs of dementia are through training, although it is not known whether the changes in reporting of signs observed within this study have impacted on practice. Whilst the aforementioned changes were apparent from the pre-post intervention analysis, overall there were few changes noted in the first signs of dementia reported by practitioners. It is possible that the knowledge acquired from training had not been utilised often enough in clinical practice to embed it in practice. It is also possible that practitioners would give different answers to questions about what they should look for in relation to dementia (knowledge quiz) and what they actually do in practice (what are the first

signs). Eccles *et al* (1998) advise that behavioural signs are often more evident in the early stages of dementia than cognitive signs, and it is therefore encouraging that fewer practitioners reported signs within the "Behavioural change nos" category and more of them reported specific signs within the "Agitation/restlessness" and "Self care abilities" subcategories of behavioural signs of dementia following training. It is also encouraging that practitioners reported more signs in the "Emotional signs" category post-training as it is possible that this may reflect the emphasis in the training intervention on assessing the emotional state of the patient, particularly with reference to differential diagnosis of dementia and depression. Practitioners also reported more often within the "Personality/ temperament" subcategory post-training, which is helpful for carers and people with dementia in that it is a sign often noted and reported by them to their GP. This may assist in the development of a shared understanding of dementia between carers and GPs.

4.3 Clinical Implications

This study has demonstrated that there are differences in both the way carers report their concerns to primary health care practitioners, and in the way these practitioners conceptualise the first signs of dementia. Carers tend to report more specific signs relating to observable tasks, such as " putting the cutlery in the bin", whereas practitioners tend to use case-level descriptions of signs, such as "misplacing things". Although carers and practitioners may report signs within the same conceptual category, the language they use to convey their thoughts appears to be very different (see appendix 5 for response lists). When such differences exist between those who

require care and those who provide care, communication difficulties can occur and both groups may find it difficult to understand or react to the concerns and views of the other. Carers generally hold GPs in high regard (Twigg & Atkin, 1994) but still report that they feel they are not listened to (Audit Commission, 2000). This may reflect the traditional medical orientation and training of GPs, as the medical model focuses on the patient and on the identification and eradication of disease. This aspect of the medical model is unhelpful for people with dementia and their families as it ignores the fact that dementia affects the family support systems of the person with dementia as well as the person with dementia. It may also increase the difficulty that medical professionals have in conceptualising dementia and taking a proactive approach to its identification and management.

It is well established in Health Psychology that changing knowledge is usually insufficient to lead to a change in behaviour (Fishbein & Ajzen, 1976). Downs *et al* (2003) found that knowledge can be increased through the provision of an intervention. However, the transfer of knowledge into practice is difficult to measure. It could be considered that an increase in reporting of the first signs of dementia reflects increased knowledge at an academic level, but also increased awareness of what signs are important in clinical practice to signify the possibility that someone has dementia. If this is the case, then this study has shown that there has been some change in practitioners' perceptions of what signs are important following training, and that these perceptions could possibly be affected by appropriate training. Good practice guidelines in the management of dementia highlight the need to consider behavioural evidence of change, as this is usually observable earlier in the course of

the disease than cognitive change (Eccles *et al*, 1998). It is encouraging that practitioners showed an increase in their reporting of specific behavioural signs post-training as this signifies a move towards greater concordance with good practice guidelines. It is also encouraging that GPs report that one of the first important signs of dementia is an informant report, as this is also an important issue dealt with in good practice guidelines. The North of England Evidence Based Guidelines (Centre for Health Services Research and Dept of Primary Care, 1998) state that a carer's report of signs of dementia often correlates with a diagnosis of dementia, but that signs reported by people with dementia often correlate with depression. This guideline recognises that, as dementia progresses, insight is diminished and carer reports become even more important in ensuring the person continues to receive high quality care (Centre for Health Services Research and Dept of Primary Care, 1998).

Psychologists have a great deal of input to offer people with dementia and their families, particularly in the early stages of the disease. Developing coping skills can be difficult for carers but research has shown that the psychological and physical health of the person with dementia and the carer can be optimised if good coping skills are developed (Gatz *et al*, 1998; Gonzalez- Salvador *et al*, 1999; Grant & Nolan, 1993; Kitwood, 1997). Adjustment to the diagnosis is another area in which psychologists can be actively involved. Previous research has shown that the fears of health care practitioners and carers about telling the person that they have dementia are largely unfounded, and that individuals with dementia want to make that choice for themselves. Psychologists also have much to offer in terms of training and consultation for other health care disciplines, as much of the work on managing

behavioural problems and developing coping strategies has been carried out by psychologists, as well as more recent work on cognitive training and rehabilitation (Clare *et al*, 1999; 2000; 2005; SIGN, 1998;2006).

4.4 Methodological Issues

4.4.1. Sample

As this study involved the use of data collected previously (Downs *et al*, 2003), it was not possible to alter the size of the study sample or to further develop some of the reports given by participants. Whilst the study sample appeared large at the outset, within individual categories of response, numbers were at times small and analysis was not possible, or required some caution in interpretation. Thus, it is possible that the current study may have lost some of the medium or small effect sizes. Due to the exploratory nature of this study, it was considered important to highlight even small differences. However, such differences can only be used as potential markers for future research.

Although individuals in the practitioner sample were not compared at an individual level, the profile of the sample at practice level was considered to be representative in terms of having a mix of urban and rural practices, and list sizes comparable with practices across the UK. The 35 practices involved in the study had a combined total of 225,740 registered patients, including 13,068 aged 75 or over (5.8 per cent). This is comparable to a general population figure of 6 per cent in Scotland and 5.6 per cent in the relevant districts of London. Therefore, practitioners were working within

practices that were representative of primary care service provision (Office for National Statistics, 2001). Comparability is an important factor in enhancing the generalisability and reproducibility of the study. However, there is a possibility that those who participated in the research were less or more motivated or less or more knowledgeable about dementia than those who refused participation. Therefore, the representativeness of the sample cannot be fully guaranteed. This issue remains a pertinent and difficult one for all clinical research, as information about non-responders is very rarely available.

4.4.2. Design

The use of a mixed within-between participants design was chosen to maximise the outcomes from the study, and make best use of the data available. As this was an exploratory study, the choice of statistical tests was intended to maximise the chance of highlighting statistically significant relationships between variables. Comparison of means for some variables allowed an insight into what factors may have an effect on participants' perceptions of first signs of dementia. However, small numbers in some reported categories reduced the power of tests. This affords merely an indication that some factors may impact on the reporting of certain signs, but could be used as a marker for possible factors in future research. The use of chi-square tests was again intended to maximise the chance of highlighting significant associations or differences between variables, but due to the exploratory nature of the study, findings were not predictive of the direction of effect.

Within the current study, no attempt was made to consider the effect of carer stress on responses to questions about the first signs of dementia, although a measure of carer burden was completed in the original Downs *et al* study. In retrospect, it would perhaps have been useful to use this as a measure of carer wellbeing, as general health has been shown to affect carers perceptions of their own health (Argimon *et al*, 2004) as well as that of their relative with dementia (Ballard, 1996). There may have been some effect of burden on the signs reported by carers but this factor has not been considered in the current study. However, the utility of this would have been limited with carers other than those whose relative was very recently diagnosed, as many other confounding factors could affect their responses if diagnosis was some time ago, as was the case for many carers in Downs *et al* (2003). Whilst stricter control over the time since first concerns were expressed by carers would have made the study more rigorous, it would have greatly depleted the data available for analysis. In future research, it may be pertinent to consider the effect of carer burden on their perceptions of the first signs of dementia and on which signs they report.

The use of both qualitative and quantitative methods within this study was chosen to enhance the richness of the findings. Qualitative data analysis allowed the author to become immersed in the data to a greater degree, and to compare both the quantity of responses and the language used by carers and practitioners to describe their experience of particular phenomena. This was useful in speculating on possible reasons for the findings from the study, and in considering what factors may be important to carers and practitioners when they observe changes in their relative or patient which causes them to consider that the person may have dementia. The

production of a complete list of categories and responses within those categories could be tested further for their utility in future research. This information could also usefully be utilised in further training for both groups to assist in the development of shared models of understanding.

4.4.3. Measures

This study used measures already utilised by Downs *et al* (2003) study when measuring knowledge of dementia of both carers and practitioners. These measures were piloted and validated before use and had high reliability coefficients, but had been developed for use by Downs *et al (2003).* Future research may wish to consider the use of newer measures that may be more reflective of current practice in dementia care, as a more accurate measure of knowledge may be gained by this approach.

4.5 Future Research

The ideas presented below follow on from the present research as factors that ought to be considered in future research into the reporting of first signs of dementia by carers and health care practitioners.

4.5.1. Changing demographics in family structure

As well as older people becoming a more prevalent group within developed and developing nations, there has also been a move for some years towards more dispersed

families. This has reflected the changes in work and social patterns in our society, such as mothers returning to work after having children, improved transport links allowing people to work further from home, the advent of new technologies that allow multinational working at local level, and the substantial rise in home ownership in the UK. However, these factors impact on the availability of family members to take on a caring role.

The UK is also increasingly a multinational population, and ethnic diversity is part of daily life. This study did not consider the experience of participants from different ethnic backgrounds, who may have very different experiences and perceptions to report. Further research using the categorisation of signs developed in this study could highlight the differences and similarities in the experience of ethnic groups experiencing, or caring for a relative with, dementia. This would be helpful in individualising care and in understanding that what they may report may require a different perspective from that currently taken in generalised health care services.

4.5.2. Changing demographics in health care

The impact of the changes in demographic profile of the population has been considered in relation to its effect on the number of older people in society. This changing profile will also affect the demographic profile of staff in the health care system. Many health care professions, including psychology, medicine and nursing, are understaffed at present and many Health Boards have included hospital closure in their strategic planning reports in an effort to fully staff important clinical areas. The

new contracts for Consultants, hospital doctors and GPs will also impact on the care available to people with dementia. An evaluation of the effect of understaffing, stretched service provision and staff whose access to training may be limited is necessary to evaluate how these factors impact on the ability of people with dementia and their relatives to report their concerns about dementia. Early recognition is recognised as an indicator of good practice (Audit Commission, 2000; 2004) and can improve access to psychological treatment in the earlier stages of the condition (Clare *et al*, 2005), as well as offering caregiver support at an earlier stage (Twigg & Atkin, 1994).

4.5.3. Condition Severity

The severity of relatives' dementia as perceived by carers was not measured directly in this study, but it is possible that carers reported signs that were not present from the first stages of their relatives' condition. With any retrospective study, there is the possibility that reports from respondents will be influenced by information gained since the original event, by current life circumstances, and by levels of stress, burden and satisfaction with caring. Greater severity of dementia would be expected to be associated with an increase in stress-related situations, however this has not always been the case in previous research. Andren & Elmstah (2005) demonstrated that the degree of burden felt by carers in their caring role, and the severity of the person's dementia, were not predictive of lower scores on the Carers' Assessment of Satisfaction Index. There are mediating factors in caring, related to the carers feelings of satisfaction in doing the best they can for their relative (Grant & Nolan, 1995). Further work with carers looking at their perceptions of dementia could focus not only

on their concerns about their relative, but also the coping mechanisms they utilized to manage the problems they encountered or anxieties they had. It would also be useful in future research to compare carers whose relative was very recently diagnosed with dementia about the earliest concerns they had about their relative, and to explore these in much more detail. Post-intervention carers in the Downs *et al* (2003) study were identified by practices as having a relative diagnosed since the intervention was put in place, and were therefore able to supply some information to the research team that related to a recent diagnosis. However, in some cases these carers had expressed concerns some considerable time before the practice intervention, particularly in urban areas, but had not been flagged up by practices at the pre-intervention stage. There were also a much smaller number of carers in this group, and data from them has therefore not been analysed within the present study. The categories arising from the present study could usefully be utilised in further work with carers whose relative has very recently been diagnosed.

4.5.4. Personality issues

Although this study did not look at the issue of perceptions of dementia held by people with different personality traits, it would be useful to consider this issue in future research. The perceptions of the impact that dementia will have on the person with dementia, their role in the family and their future functional ability may be mediated by the personality traits of the individual carer or practitioner. This perception may then affect their future interactions with the person with dementia. In further explorations of the perceptions of first signs of dementia, it would be interesting and informative to include a personality measure.

4.5.5. Summary

In summary, further research into perceptions of dementia should be encouraged to determine health care practitioners' knowledge of the condition, its varying presentations, and its impact on the psychological and physical health of those affected and their families. Further exploration may also help to reduce the traditional therapeutic nihilism regarding the care of people with dementia that still exists, and assist in the planning of effective, timely services for this group. The results of such exploration could also be utilised in the strategic planning of training for practitioners in the diagnosis and management of dementia.

4.6 Concluding Remarks

Dementia is a chronic condition affecting up to one in every five older adults over the age of 80. It is a condition that has an effect not only on the physical, psychological and social wellbeing of the person with dementia, but also on that of their family and community. The population of older adults within Western and in non-Western societies is rising, particularly in urban areas of Western societies (Kinsella, 2001) and is predicted to continue to rise disproportionately in relation to the number of younger adults within the population (Eurostat, 2004). It is therefore likely that the trend for older people with dementia to be cared for at home by relatives and informal carers will continue. Health care provision for people with dementia can be difficult due to the complexity of the condition, the knowledge and confidence of the practitioners responsible for its delivery and the fact that the level of input required can be

disproportionate to the severity of the condition. In addition to these factors, the predicted pattern of demographic change means that it is becoming more important than ever before that practitioners are aware of, and can assess for, the early signs of dementia. As discussed, previous research has highlighted that the area in which practitioners report most difficulty and lowest levels of confidence is in recognising and reporting the first signs of dementia, and that when they do suspect dementia there is often a sense of nihilism with regards to treatment options. However, it is this nihilism that can lead to the person with dementia experiencing delays in accessing assessment, diagnostic and therapeutic options for the management of their condition. Developments in the psychological, social and pharmacological treatment of dementia cannot be utilised by the person with dementia if the gatekeepers to those services do not recognise and manage dementia at an early stage. This has increasingly been recognised by statutory agencies and it is encouraging that the government recognises that earlier diagnosis and access to specialist, tailored services is both a right and a need for people with dementia. Previous studies have also reported that family carers have not felt listened to when they report their initial concerns about their relative to primary health care practitioners. Good practice guidelines have highlighted the importance of listening to carers (Eccles *et al*, 1998), and their needs as carers have been recognised in law since the Carers (Recognition and Services) Act was passed in 1995. It is disheartening that relatives continue to report they feel they are not listened to when they report their concerns about their relative's cognitive status to their primary care team (Audit Commission, 2000; Downs *et al*, 2003). It is known that the outcome for poorly supported carers is that they may also suffer ill health and psychological distress (Coope *et al*, 1995; Ballard *et al*, 1996). It is therefore

encouraging that this study highlights that at least some GPs consider informant report to be an important part of dementia diagnosis.

The current study attempted to explore and contribute to the understanding of the interaction between demographic, social, occupational, and knowledge related factors that influence the first signs of dementia reported by those involved in caring for people with dementia formally and informally. Evidence of significant relationships between the variables that were examined illustrates the importance of considering the carers' sociodemographic profile, relationship with significant others and knowledge about their relatives' condition to improve the effectiveness of communication between those who care informally for people with dementia and those who provide health care. The significance of assessing and listening to both the person with dementia and their carers' views in their journey from reporting initial concerns through to diagnosis and management of their illness has been highlighted throughout this study. It is important that people with dementia and their carers are listened to, and their concerns validated and explored. It is equally important that the practitioners who remain on the front line of health care are equipped for the challenges which dementia can pose, and are given the support and training required to feel confident, knowledgeable and proactive in all their interactions with people with dementia and their families, but particularly in the crucial early stages of the persons' journey through dementia.

5 References

Alzheimer's Scotland (2000). *Planning Signposts for Dementia Care Services.* Alzheimer's Scotland: Action on Dementia, *Edinburgh.*

Alzheimer's Disease Society. (1995a). *Right from the start: Primary health care and dementia.* London: *Alzheimer's Disease Society.*

Alzheimer's Disease Society. (1995b). *Dementia in the community: Management strategies for general practice.* London: *Alzheimer's Disease Society.*

Alzheimer's Society press release, *NICE declares drugs for dementia too expensive to be prescribed on NHS*, February 2005

Alzheimer's Disease International. (1999). *The prevalence of dementia: factsheet 3. London:* Alzheimer's Disease International

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition. Washington D.C.: *American Psychiatric Association.*

Andren, S., & Elmstah, S. (2005) Family caregivers' subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. *Scandinavian Journal of Caring Sciences, 19,* 157–168

Argimon, J.M., Limon, E., Vila, J., & Cabezas, C. (2004). Health-related quality of life in carers of patients with dementia. *Family Practice, 21,* 454-7

Arrieta, J.L., & Rodriguez, F.R. (1988). Methodology, results and quality of clinical trials of tacrine in the treatment of Alzheimer's disease: a systematic review of the literature. *Age and Ageing, 27,* 161-179.

Audit Commission. (2000). *Forget me not: Mental health services for older people.* London: *Audit Commission.*

Audit Commission Update. (2002). *Forget me not 2002: Developing mental health services for older people in England.* London: *Audit Commission, 2002.*

Audit Commission. (2004). *Older people – independence and well-being.* London: *Audit Commission, 2004.*

Bäckman, L. (1996). Utilizing compensatory task conditions for episodic memory in Alzheimer's disease. *Acta Neurologica Scandinavica, Suppl.165,* 109–113.

Ballard, C.G., Eastwood, C., Gahir, M., and Wilcock, G. (1996). A follow up study of depression in the carers of dementia sufferers. *British Medical Journal, 312,* 947.

Barnett, E. (2000). *Including the person with dementia in designing and delivering care: 'I need to be me!'.* London: Jessica Kingsley

Barrett, J.J., Haley, W.E., Harrell, L.E. and Powers, R.E. (1997). Knowledge about Alzheimer's disease among primary care physicians, psychologists, nurses and social workers. *Alzheimer Disease and Associated Disorders, 11,* 99-106.

Bartus, R.T., Dean, R.L., Beer, B., & Lippa, A.S. (1982). The cholinergic hypothesis of geriatric memory dysfunction. *Science, 217,* 408-414

Beatty, J. (1995). *Principles of behavioural neuroscience.* (pp. 100-109). USA: Brown and Benchmark.

Brandt, J., & Rich, J.B. (1995) Memory disorders in the dementias. In Baddeley, A.D.,Wilson, B.A., & Watts, F.N. (Ed). *Handbook of Memory Disorders.* Chichester: John Wiley & Sons Ltd.

Briggs, K. & Askham, J. (1999). *The needs of people with dementia and those who care for them.* London: *Alzheimer's Society.*

Bryans, M., & Wilcock, J. (2001). Issues for nurses in dementia diagnosis and management. *Nursing Times, 97,* 44; 30.

Bryans, M., Keady, J., Turner, S., Wilcock, J., Downs, M., & Iliffe, S. (2003). An exploratory survey into primary care nurses and dementia care. *British Journal of Nursing, 12,* 1029 – 1037.

Cheston, R., & Bender, M. (2000). *Understanding dementia: The man with the worried eyes.* London: *Jessica Kingsley.*

Chew, C., Wilkin, D., & Glendinning, C. (1994). Annual assessment of patients aged 75 and over: general practitioners' and practice nurses' views and experiences. *British Journal of General Practice, 44,* 263-267.

Clare, L., Wilson, B.A., Carter, G., Gosses, A., Breen, K., & Hodges, J.R. (2000). Intervening with everyday memory problems in early Alzheimer's disease: an errorless learning approach. *Journal of Clinical and Experimental Neuropsychology, 22,* 132-146.

Clare, L., Wilson, B.A., Carter, G., Hodges, J.R., & Adams, M. (2001). Long-term maintenance of treatment gains following a cognitive rehabilitation intervention in early dementia of Alzheimer type: a single case study. *Neuropsychological Rehabilitation, 11,* 477-494.

Clare, L., Woods, R.T., Moniz-Cook, E.D., Orrell, M., & Spector, A. (2005). *Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia (Review).* The Cochrane Collaboration: John Wiley & Sons, Ltd., http://www.thecochranelibrary.com.

Clare, L., Wilson, B.A., Breen, K., & Hodges, J.R. (1999). Errorless learning of face-name associations in early Alzheimer's disease. *Neurocase, 5,* 37-46.

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K. & Gallagher-Thompson, D. (2003). Anger and depression management: psychoeducational skill training interventions for women caregivers of a relative with dementia. Gerontologist, 43, 678-89.

Coope, B., Ballard, C., Saad, K., Patel, A., Bentham, P., Bannister, C., Graham, C., & Wilcock, G. (1995). The prevalence of depression in the carers of dementia sufferers. *International Journal of Geriatric Psychiatry, 10,* 477-485.

Cutler, N.E. (1986). The third victims of Alzheimer's disease: The USC national Alzheimer's disease public opinion survey. *Unpublished manuscript:* Andrus Gerontology Center, University of Southern California, Los Angeles.

Dancey, C.P., and Reidy, J. (2002). *Statistics without maths for psychology 2nd ed.* Pearson Education Ltd, Dorset.

Davis, R.N., Massman, P.J., & Doody, R.S. (2001). Cognitive intervention in Alzheimer Disease: a randomized placebo-controlled study. *Alzheimer Disease and Associated Disorders, 15,* 1; 9.

Deickmann, L., Zarit, S.H., Zarit, J.M., & Gatz, M. (1988). The Alzheimer's Disease Knowledge Test. *The Gerontologist, 28,* 402-407.

Department of Health and the Welsh Office (1989). *General Practice in the NHS: A New Contract*. London: *HMSO.*

Department of Health (1995). *Carers' (Recognition and Services) Act.* London: *HMSO*

Department of Health (1999a). *Caring about carers: A national strategy for carers.* London: *Department of Health*

Department of Health (2001). *National Service Framework for Older People: Modern Standards and Service Models.* London: *Department of Health*

Department of Health (2005) *Government response to NICE consultation on Alzheimer's drugs, 22 March 2005.* London*: Department of Health.* **h**ttp://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/

Downs, M. (1996). The role of general practice and the primary care team in dementia diagnosis and management. *International Journal of Geriatric Psychiatry, 11*, 937-942.

Downs, M., Cook, A., Rae, C., & Collins, K.E. (2000). Caring for patients with dementia: the GP perspective. *Aging & Mental Health, 4,* 301 – 304.

Downs, M., Turner, S., Iliffe, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., & O'Carroll, R.E. (2003). *Improving the response of primary care practitioners to people with dementia and their families: A randomized controlled trial of educational interventions. Final report to the UK Alzheimer's Society*. London: *Alzheimer's Society.*

Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., O'Carroll, R., Howie, K., & Iliffe, S. (2006). Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomized controlled study. *British Medical Journal, 332,* 692-696.

Eagger, S., (1996). Searching for a treatment for Alzheimer's disease - Tales from the cutting room floor. *International Journal of Geriatric Psychiatry, 11,* 337-342.

Eccles, M., Clarke, J., Livingston, M., Freemantle, N., and Mason, J. (1998). North of England evidence based guidelines development project; guideline for the primary care management of dementia. *British Medical Journal, 317,* 802-808.

Edwards, R.M., Plant, M.A., Novak, D.S., Beall, B. & Baumhover, L.A. (1992). Knowledge about Aging and Alzheimer's Disease Among Baccalaureate Nursing Students. *Journal of Nursing Education, 31,* 127-135.

Erde, E.L., Nadal, E.C., & Scholl, T.O. (1988). On truth telling and the diagnosis of Alzheimer's disease. *Journal of Family Practice, 26,* 401-6.

EUROSTAT (2004). *European population statistics 1960-2003*. Luxembourg: Office for Official Publications of the European Communities. Retrieved from http://epp.eurostat.cec.eu.int/cache/ITY_OFFPUB/KS-BP-04-001/EN/KS-BP-04-001-EN.PDFU

Farina, E., Fioravanti, R., Chiavari, L., Imbornone, E., Alberoni, M., Pomati, S., Pinardi, G., Pignatti, R., & Mariani, C. (2002). Comparing two programs of cognitive training in Alzheimer's disease: a pilot study. *Acta Neurologica Scandinavica, 105,* 365-371.

Fishbein, M., & Ajzen, I.(1976). *Belief, attitude, intention and behaviour: An introduction to theory and research.* Reading, MA: Addison-Wesley.

Ford, K., Middleton, J., Palmer, B. & Farrington, A. (1997). Primary healthcare workers: training needs in mental health. *British Journal of Nursing, 6,* 1244-1250.

Foster, J.J. (2001). *Data Analysis using SPSS for Windows.* London: SAGE publications.

Gallagher-Thompson, D. & DeVries, H.M. (1994). "Coping with frustration" classes: development and preliminary outcomes with women who care for relatives with dementia. *Gerontologist, 34*, 548-52.

Gatz, M., Fiske, A., Fox, L.S., Kaskie, B., Kasi-Godley, J.E., McCallum, T.J. & Wetherell, J.L. (1998). Empirically validated psychological treatments for older adults. *Journal of Mental Health and Aging, 4,* 9-45.

General Household Survey (2005). Office for National Statistics, from http://www.statistics.gov.uk/cci/nugget.asp?id=1109.

Glaser, B., & Strauss, A.L. (1967) *The discovery of grounded theory.* Chicago: Aldine.

González-Salvador, M.T., Arango, C., Lyketsos, C.G., & Barba, A.C. (1999). The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry, 14,* 701-710.

Goedert, M. (1993). Tau protein and the neurofibrillary pathology of Alzheimer's disease. *Trends in Neurosciences, 16,* 460-5.

Graham, N. (1995). GPs and voluntary organizations. Letter in *British Journal of General Practice*, May 1995.

Grant, G. & Nolan, M. (1993) Informal carers: sources and concomitants of satisfaction. *Health and Social Care in the Community, 1,* 147–59.

Hall, K.A. & O'Connor, D.W. (2004). Correlates of aggressive behavior in dementia. *International Psychogeriatrics, 16,* 141-58.

Harvey, R. (1998). *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome.* London: Dementia Research Group, Imperial College School of Medicine.

Hendrie, H.C., Osuntokun, B.O., Hall, K.S., Ogunniyi, A.O., Hui, S.L., Unverzagt, F. W., Gureje, O., Rodenberg, C.A,. Baiyewu, O., & Musick, B.S. (1995). Prevalence of Alzheimer's disease and dementia in two communities: Nigerian Africans and African Americans. *American Journal of Psychiatry, 152,* 1485-1492.

Hofman, A., Rocca, W.A., & Brayne, C. (1991). The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. Eurodem Prevalence Research Group. *International Journal of Epidemiology, 20,* 736-748.

Iliffe, S. (1997). Can delays in the recognition of dementia in primary care be avoided? *Ageing and Mental Health, 1,* 7-10.

Iliffe, S., Wilcock, J., Austin, T., Walters, K., Rait, G., Turner, S., Bryans, M., & Downs, M. (2002b). Dementia diagnosis and management in primary care: developing and testing educational models. *Dementia, 1,* 11-23.

Iliffe, S., Wilcock, J., Downs, M., Turner, S., & Bryans, M. (2002a). A randomised controlled trial of educational interventions for dementia diagnosis and management in primary care. *Neurobiology of Aging, 23,* 550-1.

Iliffe, S., & Drennan, V. (2001). *Primary Care and Dementia*, Bradford Dementia Group Good Practice Guides: Jessica Kingsley.

ISD Scotland. (2004). *General Practice Workforce Statistics*. Retrieved from http://www.isdscotland.org/isd/info3.jsp?pContentID=3261&p_applic=CCC&p_service=Content.show&

Jorm, A.F., Korten, A.E., & Henderson, A.S. (1987). The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica, 76,* 465-479.

Keightley, J.& Mitchell, A. (2004). What factors influence mental health professionals when deciding whether or not to share a diagnosis of dementia with the person? *Aging and Mental Health, 8,* 13-20.

Kiecolt-Glaser, J.K., Dura, J.R., Speicher, C.E., Trask, O.J., & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine, 53,* 345-362.

Kinsella, K. (2001). Urban and rural dimensions of global population aging: an overview. *Journal of Rural Health, 17,* 314-22.

Kitwood, T. (1997) *Dementia reconsidered: The person comes first.* Buckingham: Open University

La Rue, A., Watson, J. & Plotkin, D. (1993). First symptoms of dementia: A study of relatives reports. *International Journal of Geriatric Psychiatry, 8,* 239-245.

Lobo, A.. Launer, L.J., Fratiglioni, L., Andersen, K., Di Carlo, A., Breteler, M.M., Copeland, J.R., Dartigues, J.F., Jagger, C., Martinez-Lage, J., Soininen, H., & Hofman, A. (2000). Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. *Neurology, 54, Suppl 5,* S4-9.

Lundh, U. (1999). Family carers: 2. Sources of satisfaction among Swedish carers. *British Journal of Nursing, 8,* 647–52.

Maas, M. & Buckwalter, K. (1990). *Final report: Phase II Nursing Evaluation Research.* Alzheimer's Care Unit, National Institute of Nursing Research, Rockville, MD: National Institutes of Health.

Maguire, C.P., Kirby, M., Coen, R., Coakley, D., Lawlor, B., & O'Neill, D. (1996). Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis. *British Medical Journal, 313,* 529-530.

Marzanski, M. (2000). Would you like to know what is wrong with you? On telling the truth to patients with dementia. *Journal of Medical Ethics, 26,* 108-113.

McCormick, A., Fleming, D., & Charlton, J. (1995). *Morbidity Statistics from General Practice: Fourth national study 1991-1992.* Royal College of General Practitioners, the Office of Population Censuses and Surveys, and the Department of Health, London: HMSO.

McCurry, S.M., Gibbons, L.E., Logsdon, R.G., Vitiello, M., & Teri, L. (2003) Training caregivers to change the sleep hygiene practices of patients with dementia: the NITE-AD Project. *Journal of the American Geriatrics Society, 51*, 1455-60.

McIntosh, I., Swanson, V., Power, K.G., and Rae, C.A.L. (1999) General practitioners' and nurses perceived roles, attitudes and stressors in the management of people with dementia. *Health Bulletin 57,* January 1999.

McRae, T., Relkin, N., & Knopman, D. (1998). A large scale, open-label trial of Donepezil in the treatment of Alzheimer's disease. *Neurology, 50,* suppl. 4.

Mohs, R.C., Ashman, T.A., Jantzen, K., Albert, M., Brandt, J., Gordon, B., Rasmusson, X., Grossman M., Jacobs D., & Stern, Y. (1998). A study of the efficacy of a comprehensive memory enhancement program in healthy elderly persons. *Psychiatry Research, 77,* 183–195.

Moore, S., Sandman, C.A., McGrady, K., & Kesslak, J.P. (2001). Memory training improves cognitive ability in patients with dementia. *Neuropsychological Rehabilitation, 11,* 245.

National Institute for Clinical Excellence. (2001). *NICE Guidance on the use of donepezil, rivastigmine and galantamine for the treatment of Alzheimer's disease: Technology Appraisal Guidance no.19.* London: National Institute for Clinical Excellence.

National Institute for Clinical Excellence. (2004). *Final scope - Drugs for the treatment of Alzheimer's disease.* London: *National Institute for Clinical Excellence.*

Nolan, P., Murray, E., & Dallender, J. (1999). Practice nurses' perceptions of services for clients with psychological problems in primary care. *International Journal of Nursing Studies, 36,* 97-104.

North of England Evidence-based Guideline Development Project (1998). *The primary care management of dementia.* Centre for Health Services Research and Dept of Primary Care, University of Newcastle upon Tyne.

Pinner, G., & Bouman, W.P. (2003). Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis. *International Psychogeriatrics, 15,* 279-88.

Pritchard, E. & Dewing, J. (1999). Screening for dementia and depression in older people. *Nursing Standard, 14,* 46-52.

Qizilbash, N., Whitehead, A., Higgins, J., Wilcock, G., Schneider, L., & Farlow, M. (1998). Cholinesterase Inhibition for Alzheimer Disease: A Meta-analysis of the Tacrine Trials. *Journal of the American Medical Association, 280*, 1777-1782.

Rice, K., & Warner, N. (1994). Breaking the bad news: what do psychiatrists tell patients with dementia about their illness? *International Journal of Geriatric Psychiatry, 9,* 467-71.

Rosler, M. (1999). Efficacy and safety of rivastigmine in patient's with Alzheimer's disease: International randomised controlled trial. *British Medical Journal, 318,* 633-640.

Ross, H., & Hardy, G. (1999). GP referrals to adult psychological services: A research agenda for promoting needs-led practice through the involvement of mental health clinicians. *British Journal of Medical Psychology, 72,* 75-91.

Scottish Executive. (2002). *ADDING LIFE TO YEARS - Report of the Expert Group on Healthcare of Older People*: Scottish Executive.

Scottish Intercollegiate Guidelines Network. (1998). *Interventions in the management of behavioural and psychological aspects of dementia.* Edinburgh: Scottish Intercollegiate Guidelines Network (SIGN).

Scottish Intercollegiate Guidelines Network. (2006). *Management of patients with dementia*. Edinburgh: Scottish Intercollegiate Guidelines Network (SIGN).

Secker, J., Pidd, F., & Parham, A. (1999). Mental health training needs of primary health care nurses. *Journal of Clinical Nursing, 8,* 643-652.

Secretary of State. (1995). *Disability Discrimination Act*. London: HMSO Retrieved at http://www.opsi.gov.uk/acts/acts1995/1995050.htm#aofs

Smith, A., King, E., Hindley, N., Barnetson, L., Barton, J., & Jobst, K.A. (1998). The experience of research participation and the value of diagnosis in dementia: Implications for practice. *Journal of Mental Health, 7,* 309-321.

Strauss, A.L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. SAGE publications Inc.

Strauss, A.L. (1987). *Qualitative analysis for social scientists*. Cambridge University Press.

Tariot, P.N. (2000). A 5-month randomised, placebo controlled trial of galantamine in Alzheimer's disease. *Neurology, 54,* 2269-76.

Teri, L., & Gallagher-Thompson,. D. (1991). Cognitive-behavioral interventions for treatment of depression in Alzheimer's patients. *The Gerontologist, 31*, 413-416.

Teri, L., Huda, P., Gibbons, L., Young, H. & van Leynseele, J. (2005). STAR: A Dementia-Specific Training Program for Staff in Assisted Living Residences. *The Gerontologist*, *45*, 686-693.

The Scottish Office. (1997). *A Framework for Mental Health Services in Scotland.* The Scottish Office: HMSO.

Trickey, H., Turton, P., Harvey, I., Wilcock, G,. & Sharp, D. (2000). Dementia and the over-75 check: The role of the primary care nurse. *Health and Social Care in the Community, 8 , p16.*

Turner, S., Iliffe, S., Downs, M., Bryans, M., Wilcock, J., & Austin, T. (2003). Decision Support Software for Dementia Diagnosis and Management in Primary Care: Relevance and Potential. *Aging & Mental Health, 7,* 28-33.

Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryans, M., Levin, E., Keady, J., & O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing, 33,* 461-7.

Twigg, J., & Atkin, K.(1994). *Carers perceived: Policy and practice in informal care*. Buckingham: Open University Press.

Vedhara, K., Cox, N., Wilcock, G., Perks, P., Hunt, M., Anderson, S., Lightman, S., & Shanks, N. (1999). Chronic stress in elderly carers of dementia patients and antibody response to influenza vaccination. *The Lancet, 353,* 627-631.

Wilcock, J., Iliffe, S., Walters, K., Rait, G., Austin, T., Turner, S., Bryans, M., Downs, M., Levin, E., O'Carroll, R., & Keady, J. (2002). The development of an evidence-based curriculum for dementia care training in general practice. *Education & Ageing, 17,* 217-236.

Wilson, B.A. (2002). Towards a comprehensive model of cognitive rehabilitation. *Neuropsychological Rehabilitation, 12,* 97-110.

Wolff, L.E., Woods, J.P. & Reid, J. (1995). Do general practitioners and old age psychiatrists differ in their attitude to dementia? *International Journal of Geriatric Psychiatry, 10,* 66-69.

Woods, R., Moniz-Cook, E., Iliffe, S., Campion, P., Vernooij-Dassen, M., Zanetti, O., & Franco, M. (2003). Dementia: issues in early recognition and intervention in primary care. *Journal of the Royal Society of Medicine, 96,* 320-324.

6 Appendices

6.1 Appendix I: Lothian Research Ethics Committee response

Date: Wed, 26 Jan 2005 14:57:48 +0000 [26/01/05 02:57:48 PM BST]

From:LREC <LREC@lhb.scot.nhs.uk

To: s0238410@sms.ed.ac.uk

Subject: Fwd: Re: Advice on ethics requirements

Dear Michelle
The Chair of Lothian Local Research Ethics Committee 03 has considered your query and responded. I hope this answers your question.
Regards

Liz Harden
Committee Administrator
Lothian Local Research Ethics Committee 03
Tel : 0131 536 9028
elizabeth.harden@lhb.scot.nhs.uk

Date: Tue, 25 Jan 2005 13:11:23 +0000
Subject: Re: Advice on ethics requirements
From: Christine West <a1cwest@staffmail.ed.ac.uk>
To: LREC <LREC@lhb.scot.nhs.uk>

on 25/1/05 9:58 am, LREC at LREC@lhb.scot.nhs.uk wrote:

Michelle,

If you are simply analysing previously collected data and you were one of the original investigators then you do not need further ethical approval. If you are extending recruitment or joining as a new investigator then you would need to apply for approval of an amendment to the original protocol.

Christine West
Chair, LREC Committee 3

Christine P. West, MD, FRCOG.
Consultant Obstetrician & Gynaecologist,
The Simpson Centre for Reproductive Health,
Royal Infirmary of Edinburgh,
Little France,
Old Dalkeith Road,
Edinburgh, EH16 4SU
Tel: 0131-242-2525

6.2 Appendix II: Letter of permission to utilise data

UNIVERSITY OF BRADFORD

MAKING KNOWLEDGE WORK

Bradford Dementia Group
School of Health Studies

Head of Group
Professor Murna Downs

Michelle Bryans
128 Warriston Street
Carntyne
Glasgow G33 2JY

26 August 2005

Dear Michelle,

Improving the response of primary care practitioners to people with dementia and their families: A randomised controlled trial of educational interventions

This is to confirm that, as grantholder of the above Alzheimer's Society Dykes Award Study, I have given you permission to carry out a new analysis of the data collected for the study.

With best wishes,

Murna Downs

Professor Murna Downs

Unity Building 25 Trinity Road Bradford West Yorkshire BD5 0BB UK
Tel 01274 233996 Fax 01274 236395 www.bradford.ac.uk/acad/health/dementia.htm

6.3 Appendix III: Practitioner Knowledge Quiz

Practitioner Knowledge Quiz

(NB. Correct responses highlighted in Bold)

Please answer the following questions from your current knowledge without consulting colleagues or reference materials. Indicate your answer to each question by <u>circling only one of the responses.</u>

1. A GP with a list of 1,500 – 2,000 patients can expect to have the following number of people with dementia on their list:

A. 1-6	**1**
B. 7-11	**2**
C. 12-20	**3**
D. 21 or more	**4**
E. I don't know	**5**

2. By 2021, the prevalence of dementia in the general population in the UK is expected to:

A. Decrease slightly	**1**
B. Remain approximately the same	**2**
C. Increase slightly	**3**
D. Nearly double	**4**
E. I don't know	**5**

3. One of the risk factors for the development of Alzheimer's disease is:

A. Hardening of arteries	**1**
B. Age	**2**
C. Nutritional deficiencies	**3**
D. Exposure to aluminium	**4**
E. I don't know	5

4. All of the following are potentially treatable aetiologies of dementia except:

A. Hypothyroidism	**1**
B. Normal pressure hydrocephalus	**2**
C. Creutzfeldt-Jacob disease	**3**
D. Vitamin B12 deficiency	**4**
E. I don't know	**5**

5. A patient suspected of having dementia should be evaluated as soon as possible as:

A. Prompt treatment of dementia may prevent worsening of symptoms	**1**
B. Prompt treatment of dementia may reverse symptoms	**2**
C. It is important to rule out and treat reversible disorders	**3**
D. It is best to institutionalise someone with dementia early in the course of the disease	**4**
E. I don't know	**5**

6. Which one of the following procedures is required to definitely confirm that symptoms are due to dementia?

A. Mini-Mental State Exam	**1**
B. Post mortem	**2**
C. CAT scan of the brain	**3**
D. Blood test	**4**
E. I don't know	**5**

7. Which of the following is not a necessary part of the initial evaluation of someone with possible dementia?

A. Thyroid function test	**1**
B. Serum electrolytes	**2**
C. Vitamin B and folate levels	**3**
D. Protein electrophoresis	**4**
E. I don't know	**5**

8. Which of the following sometimes resembles dementia?

A. Depression	**1**
B. Acute confusional state	**2**
C. Stroke	**3**
D. All of the above	**4**
E. I don't know	**5**

9. When a patient develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with the diagnosis of:

A. Alzheimer's disease	1
B. Acute confusional state	2
C. Major depression	3
D. Vascular dementia	4
E. I don't know	5

10. Which of the following is nearly always present in dementia?

A. Loss of memory	1
B. Loss of memory and incontinence	2
C. Loss of memory, incontinence and hallucinations	3
D. None of the above	4
E. I don't know	5

11. Which of the following clinical findings best differentiates vascular dementia from Alzheimer's?

A. Word finding problems	1
B. Short term (2 minute span) visual memory loss	2
C. Stepwise disease course	3
D. Presence of depression	4
E. I don't know	5

12. The effect of anti-dementia drugs is to:

A. Temporarily halt the disease in all cases	1
B. Temporarily halt the disease in some cases	2
C. Temporarily halt the disease in some cases but often causing liver damage	3
D. Permanently halt the disease in some cases	4
E. I don't know	5

13. Which statement is true concerning the treatment of people with dementia who are depressed?

A. It is usually useless to treat them for depression because feelings of sadness and inadequacy are part of the disease **1**

B. Treatments of depression may be effective in alleviating depressive symptoms 2

C. Anti-depressant medication should not be prescribed **3**

D. Proper medication may alleviate symptoms of depression and prevent further intellectual decline **4**

E. I don't know **5**

14. Which of the following best describes the functions of the Alzheimer's Society?

A. Central research, information and campaigning role **1**

B. Provision of local support and education to carers **2**

C. Providing day and home care for people with dementia **3**

D. All of the above **4**

E. I don't know **5**

Thank you for completing this questionnaire

Questions 3, 4, 7, 9 and 11 taken from: Barrett JJ, Haley WE, Harrell LE, Powers RE. Knowledge about Alzheimer's disease among primary care physicians, psychologists, nurses, and social workers. *Alzheimer's Disease and Associated Disorders* 1997; 11: 99-106. An 'I don't know' option has been added to each question.

Questions 2, 5, 6, 8, 10, 12, 13 and 14 taken from: Dieckman L, Zarit S, Zarit J, Gatz M. The Alzheimer's disease knowledge test. *Gerontologist* 1988; 28: 402-407.

Question 1 developed by the research team, based on current estimates of epidemiology

6.4 Appendix IV: Carer knowledge quiz

Carer knowledge quiz

Carer Quiz: 20 QUESTIONS ABOUT DEMENTIA

Please read each statement and then CIRCLE TRUE OR FALSE in the right hand column. Don't worry if you are not completely sure of your answer, just put what you believe to be the case. If you have no idea if a statement is true or false, just circle "Don't Know".

1 There is only one kind of dementia	TRUE	FALSE	DK
2 In the early stages, dementia is impossible to diagnose	TRUE	FALSE	DK
3 The onset of dementia is always rapid	TRUE	FALSE	DK
4 Certain physical tests are necessary to reliably diagnose dementia	TRUE	FALSE	DK
5 Some treatable conditions can cause similar symptoms to dementia	TRUE	FALSE	DK
6 Dementia can be caused by strokes	TRUE	FALSE	DK
7. Dementia is a normal part of growing old	TRUE	FALSE	DK
8. Depression in an older person can be mistaken for dementia	TRUE	FALSE	DK
9. There is little value in diagnosing dementia at an early stage, as nothing can be done	TRUE	FALSE	DK
10. Dementia always follows a steady, progressive downhill course	TRUE	FALSE	DK
11. Pain and physical illness can make a person with dementia more confused	TRUE	FALSE	DK
12. Once someone has been diagnosed with dementia you should take over as many tasks as possible to reduce stress	TRUE	FALSE	DK
13. People with advanced dementia always need residential care	TRUE	FALSE	DK
14. Medication is the best treatment for difficult behaviour among people with dementia	TRUE	FALSE	DK
15. Falls occur more often among people with dementia who are still physically able	TRUE	FALSE	DK

16. All stimulation should be avoided for people with advanced dementia	TRUE	FALSE	DK
17. Maintaining a routine is important for people with dementia	TRUE	FALSE	DK
18. Physical exercise increases stress levels in people with dementia	TRUE	FALSE	DK
19. People with dementia often have greater nutritional needs than others of the same age and activity level	TRUE	FALSE	DK
20. The most you can expect from current drug treatments for dementia is that they might work, but only for a limited time	TRUE	FALSE	DK

Questions 1, 16, 17 & 18 adapted from Maas, M. & Buckwalter, K. (1990). Final report: Phase II Nursing Evaluation Research: Alzheimer's Care Unit [NINR]. Rockville, MD: National Institutes of Health.

Questions 6, 7 & 8 developed from a survey conducted by Cutler, N.E. (1986), University of Southern California.

Remaining questions developed for use in this study, based on current research in the field.

6.5 Appendix V: Alzheimer's Society classification system

Clinical features of dementia

An individual's pathway through dementia is unique and influenced by their previous life experience. Some of these changes may not appear in the order listed. Some may not appear at all.

	EARLY STAGES	LATER STAGES
motional anges	Shallowness of mood Lack of emotional responsiveness and consideration of others Depression and/or anxiety	Irritability and hostility Aggression
ognitive anges	Short-term memory deficit with particular difficulty in registration and recall of new information Thinking becomes concrete with a reduced range of concerns Perseveration of thoughts and actions, accompanied by repetitive speech	Language disorder. Both receptive and expressive dysphasia can occur Thought process becomes fragmented, so that speech becomes disordered and fragmented Psychotic features occur in 30-40% Persecutory ideas and delusions Auditory and visual hallucinations – not mood congruent
havioural anges	Social withdrawal Emotional and physical disinhibition Difficulty in carrying out purposeful tasks: domestic tasks, dressing etc Socially inappropriate behaviour, self-neglect Disorientation progressively for time, place and eventually for person	Wandering and restlessness Evening and nocturnal restlessness prominent Turning night into day Aggression and violence
ysical anges	Usually in later stages	Weight loss Self-neglect Malnutrition Incontinence Receptive and expressive dysphasia Bradykinesia Tremor Epileptiform seizures (usually late) Emergence of primitive reflexes Rigidity (usually late) Instability Visuospatial problems – less able to compensate for physical disabilities Immobility ('off the legs')

6.6 Appendix VI: Categorised participant responses

Categorised participant responses

Main category	Subcategory *(description)*	Practitioner responses coded within category	Carer responses coded within category
Cognitive signs	Memory impairment: (non-specific) *(memory impairment mentioned, inability to remember things)*	Awareness of memory decline Deteriorating memory Early memory loss Impaired memory (early) Impaired memory and recall Long term memory loss Loss of memory Memory impairment Memory loss Memory loss (recall events) Memory loss that worries patient and they recognise as more than usual Memory problems Poor memory Recent memory loss Self report of memory loss Unexplained memory loss	Can't remember names of people or familiar faces Could never remember Couldnae mind things, simple things Couldn't remember names of well known people or recognise familiar faces & family Didn't remember appointments. Difficulty retaining information I noticed she didn't remember things Losing his memory Losing memory Loss of memory Memory Memory affected Memory declined Memory failing Memory getting poorer Memory getting worse Memory loss Memory poorer Memory slipping Not remembering things Problems with memory Recent memory loss Very slight memory loss
	Short term memory impairment *(short term memory, memory of recent events, etc mentioned)*	Deteriorating short term memory Difficulties with short term memory Difficulty remembering recent Failure of short term memory Impaired short term memory Loss of memory (more recent episodes)	Can't recall new information Short term memory Short term memory getting iffy Short term memory getting much worse Short term memory loss Short term memory poor Short term memory poorer

	Short term memory impairment (cont.)	Loss of memory (recent especially) Loss of memory for recent events Loss of short term memory Loss recent memory Marked short term memory loss Memory loss – especially recent memories Memory loss (especially short term) Objective evidence of short term Poor memory (short term) Poor short term memory Recent memory loss Short term memory impairment Short term memory loss	Short term memory worsening
	Being forgetful *(mention of forgetting, forgetful, forgetfulness)*	Forget to eat Forgetful Forgetfulness Forgets appointments Forgetting Forgetting appointments Forgetting familiar people Forgetting medication Forgetting names Reported forgetfulness	Absent-minded Family noticed increasing Forgetfulness Forget where left things Forgetful Forgetfulness Forgets things that have happened recently Forgetting everyday tasks Forgetting faces Forgetting how much food she had bought Forgetting names and places Forgetting names of familiar people like neighbours Forgetting new information Forgetting new information quickly Forgetting people Forgetting routine things that she always did Forgetting shopping Forgetting tasks Forgetting tasks halfway through Forgetting things

	Being forgetful (cont.)		Forgetting things quickly Forgetting what I was saying to him Forgetting when people had visited Forgetting where she had put things eg, purse, keys,etc Forgetting who people were including husband Forgot time and day of week General forgetfulness Getting forgetful Getting more forgetful Getting very forgetful Went forgetful
	Cognitive change *(change in cognitive or intellectual capability, including mention of tests, scores,etc)*	Cognitive decline Cognitive deficiency Cognitive disturbance Cognitive impairment Decreased cognitive ability Decreased mental test score Decreasing cognitive function Dementia score (cognitive function) Global deterioration in cognition Impaired intellectual capacity Intellectual change Loss of cognitive powers Loss of cognitive powers Low MSQ score Mini-mental state exam score MMSE <25/30 MMSE score reduced Reduced mental faculties Reduced score on mental state questionnaire Repeated poor performance on abbreviated mental test score	Failed a question on over 75 check by health visitor

	Executive function problems *(mention of attention, concentration, planning, reasoning, judgement, problem solving, calculation, abstract thinking)*	Reduced attention span Inability to concentrate Loss of concentration Poor concentration Reduced concentration Concentration problems Difficulties understanding more than 1 concept at a time Deteriorating planning and organisation Unable to problem solve Unable to decide on things Difficulty with simple calculation Impairment of abstract thinking Impaired judgement Difficulties with calculation and attention Poor attention span Inability to sustain attention	Getting more difficult to see solutions to problems Having problem solving difficulties
	Language disorder *(reference to ability to use spoken language)*	Agnosia Answering loss Communication difficulties Difficulty finding appropriate words during normal conversation Difficulty in defining words Language difficulties Losing words Naming objects No comprehension Poor flow of conversation Speech not making sense Unable to answer questions Unable to hold conversation Unable to sustain coherent account Vague inaccurate answers to specific questions Vague speech	Calling objects by the wrong name Losing track of conversation Problems talking Saying silly things Speech difficulties Speech difficulties – word finding Talked gibberish (talking rubbish) Two thirds of the way through sentences she went off on a tangent and can't find words Vague, couldn't converse much

	Psychiatric phenomena excl. mood *(Hallucinations, delusions, obsessions, paranoia, confabulation)*	Confabulation Delusions Fixation with needing to do things obsessively Hallucinations Hallucinations auditory/visual Mistrust Paranoia Paranoid ideas Speaking about dead relatives as if alive Visual hallucinations with no other cause	Accusatory and suspicious Accusing wife of having affairs Beginning to make things up. If she didn't know the answer she'd make it up - really ridiculous things Fixating on one event and getting upset about it Obsessional behaviour Refers to dead people Saying people coming into her flat Saying people stealing keys, rays coming in through window and burning the bottom of her toaster Telling lies Very frightening hallucinations about rats
	Perseveration and repetition *(Perseveration/ repetition of speech or actions)*	Repeat some words Repeat themselves Repeated statements and questions Repeated stories about long term memory events Repetition Repetition of an idea or thought Repetition of phrases/questions Repetition of stories Repetitive behaviour Repetitive consultation Repetitive conversation Repetitive speech Repetitiveness	Actions becoming repetitive Asking same questions Asking same questions repeatedly Asking wife to repeat things Becoming more repetitive in shorter space of time Buying the same things in the shops repeatedly Constant questioning Focused on one thing repetitively Kept repeating herself Questioning carers Repeating herself Repeating questions Repeating self Repeating stories Repetition Repetition of conversation Repetition of information Repetition of purchases at shops Repetition of questions Repetitive checking

	Perseveration and repetition (cont.)		Repetitive questioning Repetitive questions and conversation Saying some things again and again
	Being confused *(Reference to confusion, being muddled or mixed up)*	Confused about days and nights Confused about time and place Confusion Confusion over tablets Confusion re medication Easily confused Getting muddled Intermittent confusion Mild to moderate confusion Mixed up re names, days, etc Repeated muddling of appointments Subjective sense of being confused Unexplained confusion	Becoming muddled Confused Confused over money Confused over things that had been routine Confusion Confusion increasing Confusion of names Extremely confused after hip replacement Getting confused Getting confused when asked to carry out tasks Getting confused with tying laces Getting more confused Increased confusion More confused than before More confused when she came out after operation Muddled
Emotional signs	Emotional change (non-specific) *(Reference to non-specific mood change)*	Changes in mood Emotional upset Mood change Mood changes Mood disturbance	Changes in mood Emotional changes Mood swings Mood change
	Personality/ temperament change *(reference to non-specific personality or temperament change)*	Change in personality Change of personality Change of temperament Personality and temperament changes Personality change Personality deterioration worsening during acute physical illness Subtle changes of personality	Personality changed Personality changes Subtle changes in personality

	Depressed mood *(depression, low mood)*	Apparent depression Clinical depression Depression Low mood Mood changes eg, depression Mood swings Often seem depressed	Negative when asked how she was
	Anxiety *(anxiety, fretting, worrying)*	Anxiety Anxiety about change Anxiety for no obvious reason Anxiety with no obvious precipitant	Becoming very anxious Fret more
	Irritability/ hostility *(irritable, hostile, argumentative)*	Becoming irritable Increased irritability Irritable	Became very argumentative Becoming huffy Becoming very adamant that she was right Getting more difficult
	Lack of emotional response/ lability *(lability, unreactive)*	Emotionally labile Emotional lability Blunting of affect in social situations	Emotionally distant No show of emotion She was not reactive Vacant at times
Behavioural signs	Behavioural change (non-specific) *(mention of non-specific change in behaviour, disturbance, decreased coping, etc)*	Abnormal behaviour for patient Behaviour change Behaviour problems Behavioural changes Behavioural difficulties Behavioural disturbance Change in functional ability Changed behaviour Changes in behaviour Changes in normal behaviour Difficulty coping at home Functional loss Impaired coping in the home Inappropriate behaviour Odd behaviour Poorer level of functioning Strange abnormal behaviour Unusual behaviour	Change in habits Didn't know what he was doing Didn't know what she was doing Doing silly things Peculiar behaviour Strange behaviour

	Withdrawal/ apathy *(withdrawal, apathy, lethargy, loss of interest, etc)*	Apathy Less motivation Loss of interest Loss of interest in personal care Loss of interest in surroundings Reduced interest	Becoming less interested in everything going on around her Didn't want to do things Lethargic Losing interest in hobbies and interests More withdrawn in conversation No interest in anything Slowed down in activities Starting to withdraw into herself
	Agitation and Restlessness *(agitation, restlessness, wandering)*	Agitation Night time wandering Wandering Wandering especially at night	Agitated Getting agitated Used to pace about Wandering Wandering around streets Wandering away when asked to stay in one place
	Aggressive behaviour *(aggression, hitting out, violent behaviour)*	Aggression Aggression towards carer Aggressive Aggressive behaviour Unjustified anger or aggression	Get quite aggressive Difficult and aggressive all the time
	Difficulty with purposeful tasks *(domestic tasks, bills, cooking etc)*	Burning food Buying inappropriate food, not using food, stockpiling Difficulty coping with medication Difficulty doing daily tasks/bills Difficulty handling money Difficulty with activities of daily living skills Difficulty with tasks that well-managed before Impairment of daily living skills Inability to perform tasks they used to do Loss of ability to cook etc. Loss of activities of daily living	Couldn't do simple things Couldn't fold sheets any more Difficulties in remembering how to plan and carry out tasks like cooking a meal Getting mixed up over tasks or money House dirty Leaving chip pan on Leaving gas on Leaving house in a mess, would never have been untidy before Leaving oven on No longer able to do things he could previously like cook

	Difficulty with purposeful tasks (cont.)	Loss of daily living skills Loss of domestic skills Neglect of house Neglected house Not buying food Not coping with activities of daily living Unable to perform simple tasks	& shop Not using medication Problems in driving the car on new roads or unknown areas Problems using cutlery Really wasn't coping with things she'd managed so well before Turning on taps & leaving them on
	Disorientation/ getting lost *(disorientation to time/place/person, /lack of awareness of situation, getting lost)*	Disorientation Disorientation for time Disorientation in familiar surroundings Disorientation in time and place Disorientation to place Disorientation to place, time, person Errors in time or date Getting lost Getting lost when out Getting time of day wrong Loss of awareness of significant others Loss of orientation in time and space Loss of time orientation Time and place mix-up Turning night into day Unaware of day/date/month Unaware of day/time/season Unaware of time of day Vague subjective sense of disorientation	Couldn't find his way home Couldn't find the toilet Didn't recognise people Disorientated in time and to person Disorientation Getting dates mixed up Got lost locally, couldn't find his way home Got lost on holiday 2 years ago in the airport Mixing up locations and addresses Moved house and then getting disorientated No recognition of familiar people Not sure of where she was Would ask the time of day etc. and knew something was wrong Wouldn't know what day it was
	Losing/hoarding/ hiding things *(losing/misplacing things, hiding or hoarding)*	Losing things Misplacing objects Putting things in the wrong place Can't find things Hoarding food	Hiding items in the house Hiding money Hiding things Hiding things in the house Hoarding food Hoarding, hiding money

	Losing/hoarding/ hiding things (cont.)		Items going missing in the house e.g. cutlery going in the bin Losing items, keys, purse Losing money Losing purse Losing things Losing things like her purse Losing things like pension book Misplacing thins Money disappearing from the house Putting things away & forgetting where things were Putting things in wrong place Putting things where they don't belong Searching for items for a long time in wrong place
	Self care abilities *(mention of ability to wash/dress/groom, look after self/hygiene/health)*	Changes in personal care Decline in general self care Deteriorating self care Deterioration from previous levels of self care Deterioration in personal hygiene Dress/hygiene inappropriate Inability to self care Lack of care in personal appearance/ hygiene Lack of personal care Lack of self care Less careful in appearance Loss of activities of daily living and personal hygiene Loss of self care Lowering of standards of personal hygiene Neglect of self Not attending to personal care Not coping at home or with daily self care Personal hygiene	Changes in ability to wash & groom herself Not taking care of self Not washing properly Personal hygiene getting poorer Personal hygiene poor Self care abilities deteriorated Self care getting worse

	Self care abilities (cont.)	Poor hygiene – self/house Poor hygiene habits Poor personal hygiene Poor personal hygiene and care Poor self care Reduced self care Self neglect Self neglect of hygiene Self presentation declines Unable to attend to personal hygiene Unable to look after self Unkempt	
	Social behaviour *(socialisation, socially inappropriate behaviour, disinhibition, social habits, drinking, etc)*	Altered social behaviour Deterioration in social functioning Disinhibition Impaired social and occupational functioning Interpersonal reactions Loss of confidence Loss of inhibitions Poor social functioning Reduced socialising	Drinking alcohol Drinking too much Gambling Husband didn't want to go out on his own suddenly Less sociable, more withdrawn Started drinking heavily
Physical signs	Physical change (non-specific) *(mention of change in overall physical state/illness)*	Doesn't have signs of other disease Loss of smell (time magazine) Physical disability	Acute onset of illness due to burst aneurysm Started with deafness Vein problems in her leg Had had a mini-stroke Had a stroke Hearing problems (getting lots of ear infections) Irregular heartbeat Mild stroke Pneumonia admission to hospital Took wee turns Twitch in hand and leg
	Nutritional concerns *(not eating, weight loss, etc)*	Loss of weight Not eating Not eating or drinking Nutritional needs/skills	Not eating

		Weight loss	
	Mobility disturbances *(change in mobility, movement disorder)*	Apraxia Co-ordination difficulties (balance) Deterioration in complex movements Loss of motor skills Mobility problems/co-ordination Reduced mobility	Movements getting slower
	Sleep disturbance *(poor sleep, changes in pattern, etc)*	Insomnia Poor sleep Sleep changes Sleep disorder Sleeplessness	Couldn't waken in the morning Getting up during the night & waking her son More sleepy than usual
	Level of continence *(change in bladder/bowel habits)*	Continence issues Incontinence	Incontinence
	Falls *(falls/accidents)*	Accidents Falls	Fall Falls Fell and fractured hip Fell down stairs Picked up after a fall Road accident
Other signs	Informant report *(report from carers/relatives/ professionals/third party)*	Carer concerns Carer history Concern from relatives Family concerns Family noting not as alert Family or professional report of poor memory Relative/carer complains of poor short term memory Relative/informant gives symptoms of slow decline in memory and cognitive function Relative's concerns Relative's concerns re mental deterioration Report from carer/relative about reduced functioning Reports from relatives/ carers	Went in for carers allowance and it was put on the form-didnt know anything wrong before he found out it Sister asked question does mother have alzheimers Drs at hospital told him before anything noticed by carer Carer was surprised when told by Dr GP noticed vagueness and said 'it looked as though your mother has slight dementia' then he didn't say anything else

	Non-categorised *(signs reported outwith other categories)*	Difficulty coping with consultation Facial expression Inappropriate requests for visits, scripts,etc Missing appointments Not attending consultations when previously reliable Poor compliance Regression Writing lists	Had some very fanciful ideas about what one could and couldn't do Had food poisoning? due to leaving out food too long He went funny on the plane Saying she had done things but hadn't Sending money away to readers digest Spending a lot of money Things were not quite right Felt mum 'wasn't right' Not feeling herself